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PRINCIPAL INVESTIGATOR: Hayley Thompson, Ph.D.

CONTRACTING ORGANIZATION: Mount Sinai School of Medicine
New York, NY 10029

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Abstract

Breast cancer survivors are at elevated risk for developing a new breast cancer compared to healthy women, and are at considerable risk for breast cancer recurrence. According to the American Society of Clinical Oncology, survivors should undergo careful breast cancer surveillance including annual mammography and breast self-exam. However, studies indicate that breast cancer surveillance among African American survivors, particularly mammography, is low, especially given the higher risk of survivors as a group. The promotion of breast cancer surveillance among African American survivors is an area that deserves special attention as cancers detected early are more treatable. One promising strategy is the adaptation of a peer-led intervention developed to increase screening among healthy African American women. The objectives of the current study are: 1) to evaluate the impact of a peer-led intervention on breast cancer surveillance intention and adherence among African American breast cancer survivors through a randomized controlled trial; and 2) to investigate the mediational pathways through which the peer-led intervention impacts surveillance intention and adherence.

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INTRODUCTION: Breast cancer survivors are at elevated risk for developing a new breast cancer compared to healthy women, and are at considerable risk for breast cancer recurrence. According to the American Society of Clinical Oncology, survivors should undergo careful breast cancer surveillance including annual mammography and breast self-exam. However, studies indicate that breast cancer surveillance among African American survivors, particularly mammography, is low, especially given the higher risk of survivors as a group. The promotion of breast cancer surveillance among African American survivors is an area that deserves special attention as cancers detected early are more treatable. One promising strategy is the adaptation of a peer-led intervention developed to increase screening among healthy African American women. The objectives of the current study are: 1) to evaluate the impact of a peer-led intervention on breast cancer surveillance intention and adherence among African American breast cancer survivors through a randomized controlled trial; and 2) to investigate the mediational pathways through which the peer-led intervention impacts surveillance intention and adherence. 409 participants will be recruited and randomized over the course of the study. Participants will be African American women age 20-74 years and diagnosed with Stage I, II or III breast cancer who previously participated in an ongoing parent project and are at least 3 months post-treatment. Once informed consent is obtained, participants will be contacted via telephone to complete a baseline interview assessing sociodemographic information, breast cancer surveillance intention and adherence, and attitudinal/cognitive variables. Participants will then be assigned to either the survivor surveillance intervention condition or control condition and those in the intervention condition will participate in the intervention. One month following the intervention, participants in both conditions will complete a telephone interview to assess breast cancer screening adherence and changes in attitudinal/cognitive variables from baseline to post-intervention. Fourteen months after the intervention, women in both conditions will be contacted again in order to assess surveillance intention and adherence.

BODY: The approved statement of work for the current study is included as Appendix A. **Please note**: DoD Human Subject Protection Review was completed and approval received in November 2004. The notice of MSSM IRB renewal approval is in Appendix B. We are awaiting approval on amendments to the protocol submitted in November 2005 and for which MSSM IRB approval was obtained and submitted to the DoD in April 2005 and as of 4/29/05 will still being reviewed and processed. These modifications will greatly facilitate recruitment and study implementation as they describe the expansion of recruitment efforts beyond the DoD study titled, "Behavior, Estrogen Metabolism, and Breast Cancer Risk: A Molecular Epidemiologic Study," (HSRRB Log Number A-10862.5). These amendments are included in Appendix D. The documentation in Appendix D is also the current version approved by MSSM's IRB.

Tasks completed in the past year are described below.

A. **Task 2: Recruit participants, conduct baseline assessment interview for randomized controlled trial evaluating peer-implemented survivor surveillance intervention, and conduct intervention (Months 6-30)**

Since December 2004, a total of 29 women have agreed to participate (to date, participants have been identified and recruited based upon their participation in the DoD study titled, "Behavior, Estrogen Metabolism, and Breast Cancer Risk: A Molecular Epidemiologic Study," (HSRRB Log Number A-10862.5). Of these women, 13 were assigned to the intervention condition and 14 were assigned to the control condition. All of these women completed baseline interviews.

B. **Task 3: One-month follow-up assessment interviews (Months 8-30)**

Of the 27 participating women, 21 have completed one-month follow-up interviews.

D. **Task 4: Fourteen-month follow-up assessment interviews (Months 21-45)**

As recruitment began 7 months ago, no 14-month interviews have been conducted.

C. **Task 5: Interim data analyses, report and presentations (Months 22-27)**

Interim data analyses on the 29 participants has not been completed as data is still being entered and cleaned.

D. **Collaborate with co-investigators and consultants to review assessment strategies and tailoring of the survivor surveillance(peer-led) intervention:** We established weekly investigators meetings that include the PI, the project coordinator, and co-investigators (Drs. Bovbjerg and Valdimarsdottir and Ms. Jandorf). These meetings focus on recruitment and implementation issues, as well as assessment strategies.

E. **Additional training of peer interventionists:** Since June 2004, we trained 4 additional interventionists: 3 survivor speakers and 1 lay health educator. Appendix C includes an abstract describing the training of peer interventionists that was presented at the 2005 Era of Hope conference in Philadelphia, PA.

KEY RESEARCH ACCOMPLISHMENTS: The key research accomplishments since June 2004 is the presentation of an abstract describing interventionist training (see Appendix D).

REPORTABLE OUTCOMES: See abstract in Appendix D.

CONCLUSIONS: DoD Human Subject Protection Review was completed and approval received in November 2004. Since approval, 29 women have been recruited to participate in this research. We are awaiting approval on amendments to the protocol submitted in November 2005 and for which Mount Sinai IRB approval was obtained and submitted to the DoD in April 2005. These modifications will greatly facilitate recruitment and study implementation. These amendments are included in Appendix B.

Appendix A. Approved Statement of Work

Task 1: Study start-up (Months 1-5)

a. Hire and train research assistant and data entry clerk
b. Collaborate with co-investigators and consultants to review assessment strategies and tailoring of the survivor surveillance intervention
c. Train peer interventionists (recruited from the ongoing Witness Project of Harlem)
d. Pilot test and refine unstandardized measures
e. Prepare data entry and participant tracking systems

Task 2: Recruit participants, conduct baseline assessment interview for randomized controlled trial evaluating peer-implemented survivor surveillance intervention, and conduct intervention (Months 6-30)

a. Review database of parent project to identify eligible breast cancer patients
b. Recruit 409 patients for randomized controlled trial via telephone and mail informed consent forms
c. Administer baseline assessment interview for randomized controlled trial via telephone upon receipt of signed informed consent forms (expected total of baseline interviews=409)
d. Randomize participants
e. Mail incentives ($20 money orders) for participation
f. Develop schedule of survivor surveillance intervention presentations (expected total of presentations=14)
g. Begin data entry and management

Task 3: One-month follow-up assessment interviews (Months 8-30)

a. Contact participants via telephone to administer one-month follow-up assessment interviews (expected total of one-month follow-up interviews=389 with 5% attrition from baseline)
b. Mail incentives ($20 money orders) for participation
c. Continue data entry and management

Task 4: Fourteen-month follow-up assessment interviews (Months 21-45)

a. Contact participants via telephone to administer 14-month follow-up assessment (expected total of 14-month follow-up interviews=311 with 20% attrition from 1-month follow-up)
b. Mail incentives ($20 money orders) for participation
c. Continue data entry and management

Task 5: Interim data analyses, report and presentations (Months 22-27)

a. Work with co-investigators and consultants to conduct preliminary analyses for report
b. Present preliminary results at scientific meetings

Task 6: Final data analyses, report and presentations (Months 45-48)

a. Work with co-investigators and consultants to conduct analyses for report
b. Present results at scientific meetings
c. Prepare manuscripts for publication

Appendix B. Notice of renewal approval from MSSM's IRB (following page).

MOUNT SINAI
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MEDICINE

Institutional Review Board

One Gustave L. Levy Place
Box 1075
New York, NY 10029-6574

Phone: 212.659.8980
Facsimile: 212.876.6789

Date: July 7, 2005

GCO Project # 02-0561 0001 03 CA *
Principal Investigator
Hayley Thompson, Ph.D.

ARMY

Dear Sir/Madam,

The project entitled **INCREASING BREAST CANCER SURVEILLANCE AMONG AFRICAN AMERICAN BREAST CANCER SURVIVORS** includes activities involving human subjects. The Institutional Review Board of the Mount Sinai School of Medicine reviewed this project by expedited review in accordance with our assurance to the Department of Health and Human Services **FWA # 00005656.** This project met the criteria for Expedited Category **7, & 8b**. This project is approved for continuation for the period **6/29/2005** through **6/8/2006**.

Sincerely yours,

Jeffrey H. Silverstein, M.D.
Chair
Institutional Review Board
Associate Dean for Research

Appendix C. Abstract presented at 2005 Era of Hope Conference.

ABSTRACT

Women diagnosed with breast cancer are at considerable risk for breast cancer recurrence and at elevated risk for developing a second primary breast cancer compared to women in the general population. Thus, breast cancer survivors represent a high-risk population for whom careful breast cancer surveillance and follow-up care is a priority. There are disparities in surveillance such that African-American (AA) survivors were approximately half as likely to have a mammogram compared to White survivors. It has also been reported that duration of medical follow-up care for AA survivors was significantly shorter than that of White survivors. These findings suggest that the promotion of recommended breast cancer surveillance among AA survivors is an area warranting special attention.

The objectives of the current Idea Award are: 1) to evaluate the impact of a peer-led survivor surveillance intervention on breast cancer surveillance intention and adherence (mammography, BSE, pelvic exam, physical examination, patient symptom history) among African American breast cancer survivors through a randomized controlled trial; and 2) to investigate the mediational pathways through which the intervention impacts surveillance intention and adherence.

In order to reach these objectives, we have developed "Survivors in Sprit," a faith-based and peer-led educational program. Presentations include: 1) an inspirational introduction, 2) testimony by at least one breast cancer survivor about her cancer detection, survival and the importance of regular surveillance; 3) review of breast cancer recurrence facts by a lay health educator; 4) discussion of concerns and myths about breast cancer recurrence and screening/surveillance that are salient among AAW; 5) review of guidelines for surveillance as established by the American Society of Clinical Oncologists; and 6) "hands-on" breast self-exam instruction using the "grid" method, which emphasizes examination of not only the breast but adjacent areas (e.g., chest, armpit).

In developing "Survivors in Spirit (SIS)," we conducted a preliminary qualitative study that included key informant interviews of 10 AA breast cancer survivors. Survivors reported a number of factors that motivated or deterred them in obtaining follow-up care: a desire to maintain good health, worry and fear about recurrence, support from health care providers, familial relationships, lack of support from family and friends, relationships with other survivors, religious or spiritual faith, lack of information about post-treatment follow-up care, medical care costs and limited access to quality healthcare. These data were used to further develop the "Survivors in Spirit" intervention. To date, we have conducted three 5-hour training sessions during which we trained 10 breast cancer survivors (referred to as survivors speakers) and 16 lay health educators. Twenty-four volunteers completed both training pre-tests and post-tests of breast cancer recurrence knowledge. Overall, knowledge scores increased following training sessions (pre-test mean=57% correct, range=30% - 80%; post-test mean=79% correct; range=60%-100%). SIS represents a promising strategy to increase breast cancer surveillance among AA survivors.

INTRODUCTION

Among breast cancer patients diagnosed with in situ, stage I or stage II disease, studies report local recurrence rates of 5-10% at 5-year follow-up and 10-15% at 10-year follow-up. The incidence of distant recurrence is higher, between 20-35% at 10-year follow-up. Rates of contralateral breast cancer, or a new primary breast cancer have been reported between 8-10%. Thus, careful breast cancer surveillance post-treatment is warranted. However, it has been reported that AA breast cancer survivors were approximately half as likely to have a mammogram over a 2-year period compared to White survivors. Thus, breast cancer survivors represent a high-risk population for whom careful post-treatment breast cancer surveillance and follow-up care is a priority. However, disparities in surveillance exist such that AA survivors have been found to be half as likely to have a mammogram compared to White survivors. Additionally, the duration of medical follow-up for AA

survivors was significantly shorter than that of White survivors. These findings suggest that the promotion of recommended breast cancer surveillance among AA survivors is an area needing special attention.

In order to address disparities in follow-up care, we have developed "Survivors in Spirit," a faith-based and peer-led educational program. The primary aim of SIS is to increase adherence to guidelines for surveillance as established by the American Society of Clinical Oncologists (see Figure 1). Key informant interviews were conducted with breast cancer survivors of African descent in order to explore the following: recommendations received about follow-up care once primary treatment ended, the follow-up care received in the past year, and factors that are either motivators of or barriers to care. Participants were10 African-American and African-Caribbean breast cancer survivors who completed primary treatment for breast cancer at least one year before study participation. Participants were primarily recruited from patient support groups and volunteer pools of cancer education and outreach programs and all reported a single breast cancer diagnosis with no recurrence or diagnosis of a second primary breast cancer. Interviews were conducted either over the telephone or in person. Additional background information is presented in Table 1. All interviews were audio-taped and lasted between 30 and 60 minutes. An open-coding strategy was used to identify common concepts across participant responses and develop response categories. Results are presented in Table 2.

We then further developed the content of SIS presentations (see Figure 2) as well as a protocol to train interventionists. SIS presentations are conducted by two types of volunteer peer interventionist: 1) survivor speakers, AA breast cancer survivors who share their personal stories of diagnosis, treatment and follow-up care, and 2) lay health educators, non-affected AA individuals who play a more didactic role. To date, we have trained 26 volunteers who completed training pre-tests and post-tests (see Table 3). Overall, knowledge scores increased following training sessions (pre-test mean=57% correct, range=30% - 80%; post-test mean=79% correct; range=60%-100%).

Conclusion

Like other breast cancer survivors, AA survivors are at considerable risk for breast cancer recurrence or contralateral cancer. However, there are racial disparities such that AA survivors are less likely to participate in post-treatment follow-up care. Our results suggest a number of factors that influence follow-up care among AA survivors. These factors were incorporated into "Survivors in Spirit" (SIS), a peer-led and faith-based program developed to increase breast cancer surveillance among AA survivors. Peer interventionists were successfully trained to implement SIS, as evidenced by an increase in knowledge about breast cancer recurrence and ASCO guidelines pre- and post-training. SIS represents a promising strategy to increase breast cancer surveillance among AA survivors.

Appendix D. Protocol amendments under review at DoD and currently approved by MSSM (following page).

Protocol Title: Increasing Breast Cancer Surveillance Among African American Breast Cancer Survivors.

Principal Investigator: Hayley Thompson, Ph.D.

Location of Study: Mount Sinai School of Medicine, New York City

Time Required to Complete: 1/1/03 – 12/31/06

Revised: 4/11/2005

A. BACKGROUND: Women who have already been diagnosed with breast cancer are at substantially elevated risk for developing a second primary breast cancer [1]. The relative risk of developing a contralateral tumor among breast cancer survivors is between 1.5 to 5.5-fold higher than the risk of primary breast cancer in women in the general population [2-4]. Several authors have noted that survivors who have had breast-conserving surgery are at considerable risk of ipsilateral breast cancer recurrence [5-7]. There is general consensus that recurrences detected early are more treatable and the likelihood of achieving disease control, complete remission, or extended survival is higher [5;8].Thus, breast cancer survivors represent a high-risk population for whom careful breast cancer surveillance is a priority. According to the American Society of Clinical Oncology (ASCO), following primary treatment, breast cancer survivors should: 1) participate in annual mammography (with first post-treatment mammogram approximately 6 months after completion of radiation therapy); 2) conduct monthly breast self-exam (BSE); 3) undergo a regular pelvic exam; 4) undergo a physical examination every 3-6 months for the first 3 years then every 6-12 months for the next 2 years, then annually; and 5) provide a patient/symptom history every 3-6 months for the first three years after primary treatment, then every 6-12 months for the next 2 years, then annually [9]. However, data suggest that breast cancer survivors under-utilize surveillance modalities, particularly mammography. Lash and colleagues [10] report that among breast cancer survivors age 55 and older, 45% had no surveillance mammogram over a four-year period. Similarly, findings based on SEER data revealed that in a cohort of breast cancer survivors age 65 years and older, 38% did not meet ASCO guidelines for mammography over a two-year period [11]. In this cohort, African American survivors were approximately half as likely to have a mammogram compared to White survivors. These findings suggest that the promotion of recommended breast cancer surveillance among African American survivors is an area warranting special attention.

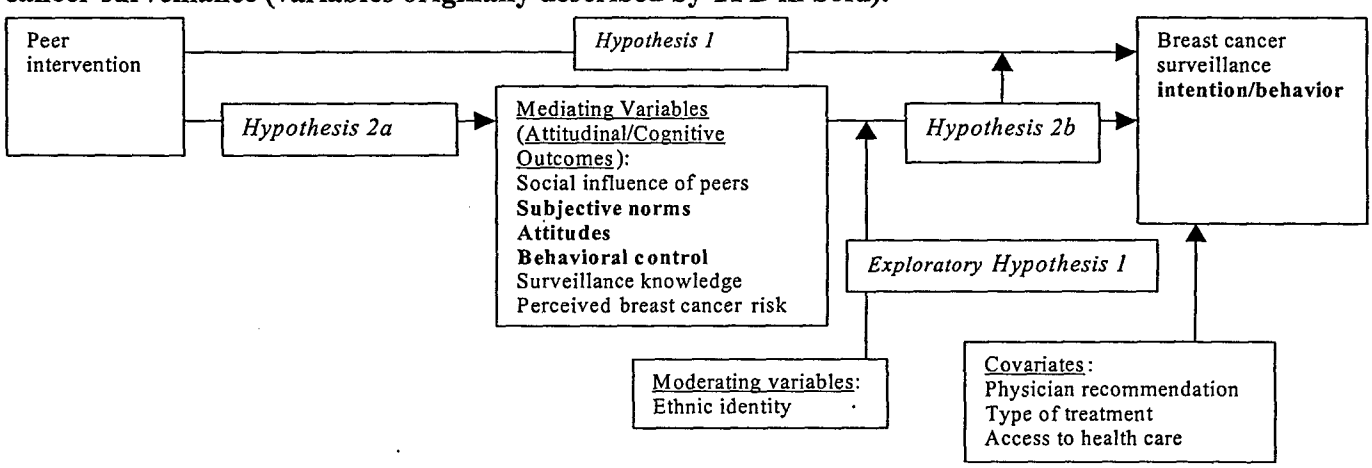
A number of factors may contribute to these surprisingly low mammography rates. Treatment factors may play a role, as survivors who received radiation therapy were significantly more likely to participate in follow-up mammography than women who did not receive radiation therapy [10;11]. Physician factors may also play a role as Lash and colleagues [10] reported that the greatest proportion of mammograms in their cohort were ordered by surgeons as opposed to other specialists, although there were no significant differences. This finding suggests that physician recommendation is likely to be an important factor, as it is with healthy women obtaining screening mammograms. Lack of physician recommendation has been found to be a significant barrier to mammography in African American women (AAW) in particular[12 13] and there are additional barriers observed among healthy AAW that may apply to breast cancer survivors. Failure to adhere to mammography guidelines is significantly associated with limited health care access [14-16 17], low breast cancer knowledge [18-21], and low perceived breast cancer risk [21-23]. Breast cancer surveillance-related fears and worries, such as fear of finding a problem, and concerns about mammography pain, have also been reported by AAW as significant barriers to mammography [21 24 25 26;27]. We are not aware of any data regarding breast self-examination (BSE) adherence among African American breast cancer survivors. However, studies of healthy AAW indicate both underpractice (less than once a month) and overpractice (more than once a month) of BSE [28;29]. BSE may be especially important among breast cancer survivors as several studies indicate that over 70% of breast cancer recurrences are detected by patients themselves as a result of their developing symptoms, such as breast changes, that were identified during the interval between scheduled surveillance appointments or are reported at the time of a scheduled appointment [30-32].

Although there is a considerable body of literature focusing on interventions to increase social support, psychological adjustment, and quality of life among breast cancer survivors, we have found no published data on interventions specially developed to increase post-treatment breast cancer surveillance. One strategy in the development of such an intervention is the adaptation of one developed to increase breast cancer screening among AAW in the general population. Peer interventions by trained lay people who are ethnically, culturally, and socioeconomically similar to the target population are especially compelling. These peer interventions have been increasingly implemented in African American populations and have been shown to increase rates of breast cancer screening [33 34-37]. One successful example of a peer intervention is The Witness Project® [38-40], a breast and cervical cancer education program that integrates the personal insights and experiences of breast cancer survivors with the expertise of lay health advisors (See Resources at MSSM). Several evaluations of this approach have revealed significant increases in screening from pre- to

post-intervention ranging from 12% - 33% for mammography and BSE [38-40]. Although peer interventions are gaining recognition as a viable approach to breast cancer prevention and control [41-43], little research has examined the sources of their success.

Two theories may inform our investigation of the impact of peer interventions. The first, reference group-based social influence theory[44], emphasizes the direct and indirect ways in which groups affect individual behavior. In terms of breast cancer surveillance, peer interventionists are potentially a source of social influence in that they are reference group members and models who: 1) emphasize group values and norms consistent with regular breast cancer surveillance and challenge or reframe group values that are inconsistent, and 2) are "similar others" whose surveillance behavior may be emulated. The influence of norms is also an element of the second theory, the Theory of Planned Behavior (TPB) [45]. TPB posits that one's behavioral intention is predicted by attitudes (one's evaluation of a behavior), subjective norms (one's perception of reference group desires that the individual participate in the behavior) and perceived behavioral control (one's appraisal of his or her ability to engage in the behavior). Studies exploring TPB variables have reported that attitudes, norms, and behavioral control were significant predictors of intention to have a mammogram [46] and intention was the strongest predictor of actual participation [47]. An integration of reference-group based social influence theory and TPB can guide an investigation of the impact of a peer intervention on surveillance (See Figure 1). We speculate that the beneficial effect of a peer intervention is mediated by increases in the following attitudinal variables: 1) survivors' perception of social influence to participate in breast cancer surveillance because the peer interventionists endorse and participate in surveillance themselves; 2) favorable attitudes among survivors because peer interventionists

Figure 1. Integration of reference group-based social influence theory and TPB to investigate breast cancer surveillance (variables originally described by TPB in bold).



address group-specific attitudes; and 3) a sense of behavioral control among survivors because peer interventionists may serve as models whose own surveillance behavior may be emulated. The impact of a peer intervention may also be mediated by increases in cognitive variables such as breast cancer surveillance knowledge, to the extent that peers are viewed as credible sources of information, especially information specific to AAW. It may also be mediated by perceived recurrence risk, as peers may emphasize the vulnerability of AAW as a group. Given our emphasis on social influence theory, it may be important to identify characteristics that vary across individuals and moderate responses to social influence. For example, if a woman has a strong ethnic identity or sense of belonging to African Americans as a group, she may be more likely to respond to social influence than one who does not have strong group ties. This has been demonstrated in previous studies [48 49] in which group norms were more strongly associated with intention and behavior when the individual's identification with the group was strong.

Resources at Mount Sinai School of Medicine (MSSM): 1) The Witness Project of Harlem (WPH; PI: Lina Jandorf, MA) is a faith-based and culturally sensitive breast cancer screening intervention coordinated based at the Ruttenberg Cancer Center, Mount Sinai School of Medicine, NYC. It was modeled after the

Witness Project developed by Deborah Erwin, Ph.D. and its mission is to increase rates of breast cancer screening among AAW in the general population. Presentations by witness role models (breast cancer survivors) and lay health advisors serve as the foundation. Since 2000, 7 witness role models and 18 lay health advisors have been fully trained to conduct WPH presentations. To date, 13 WPH presentations have been conducted and have been attended by 212 women in the community. 2) Genetic Factors in Breast Cancer: Center for Interdisciplinary Research is an ongoing Department of Defense-funded project (PI: Dana Bovbjerg, Ph.D.) at the Mount Sinai School of Medicine in NYC. The central goal of the project is to further the understanding of the impact of biobehavioral factors on genetic aspects of breast cancer in African American women. The project is primarily based upon a case-control design to examine the contribution of gene-environment interactions in breast cancer risk and has proposed to recruit 800 breast cancer patients over a four-year period (2002-2005). To date, only 3 of 43 breast cancer patients contacted have refused to participate (93% response rate) and 100% of patients have given permission to be contacfed again about other research opportunities. All participants in the proposed study will be recruited from among "graduates" of this center project. Benefits of this approach include dramatically reducing the costs of ascertainment and collection of relevant chart data while capturing a broad cross-section of all African American breast cancer cases in NYC.

B. HYPOTHESES: The objectives of the research proposed here are: 1) to evaluate the impact of a peer-led survivor surveillance intervention on breast cancer surveillance intention and adherence (mammography, BSE, pelvic exam, physical examination, patient symptom history) among African American breast cancer survivors through a randomized controlled trial; and 2) to investigate the mechanisms (mediational pathways) through which the peer-led intervention impacts surveillance intention and adherence (See Figure 1). **Hypothesis 1**: Participants in the survivor surveillance intervention condition will report greater breast cancer surveillance intention and adherence following that intervention compared to women in the control group. **Hypothesis 2**: The impact of the intervention on surveillance intention and adherence will be mediated by changes in attitudinal and cognitive variables (breast cancer surveillance-related social influence, attitudes, behavioral control, knowledge and perceived breast cancer risk). **Exploratory Hypothesis 1**: Ethnic identity will moderate the impact of the intervention such that women with stronger ethnic identity will benefit more from the intervention.

Exploratory Hypothesis 2: Ethnic identity and spirituality will moderate the impact of the intervention such that women reporting stronger ethnic identity and spirituality will benefit more from the intervention.

Exploratory Hypothesis 3: Participation in the breast cancer surveillance will be influenced by aspects of the patient/physician relationship including ethnic concordance between patient and physician, patient trust of medical professionals and settings, and quality of communication between patient and physician.

Exploratory Hypothesis 4: Participation in the breast cancer surveillance will be influenced by patient-reported emotional well-being, such as breast cancer-specific distress and concerns about recurrence.

C. OBJECTIVES: Objective 1: To evaluate the impact of a peer-led survivor surveillance intervention on breast cancer surveillance intention and adherence (mammography, BSE, pelvic exam, physical examination) among African American breast cancer survivors through a randomized controlled trial. **Objective 2**: To investigate the mechanisms (mediational pathways) through which the peer-led intervention impacts surveillance intention and adherence (See Figure 1). The proposed study will randomize 409 African American breast cancer survivors to one of two conditions: a survivor surveillance intervention condition or a control condition. All participants will complete a baseline interview assessing sociodemographic and medical information, surveillance intention and adherence, attitudinal and cognitive variables, and ethnic identity. One month following the intervention, all participants will be contacted to complete an interview to assess change in intention, adherence, and attitudinal/cognitive variables. All participants will be contacted again 14 months following the intervention to assess surveillance intention and adherence.

D. METHODS: Participants and sample size: Participants will be AAW recruited from an ongoing Department of Defense-funded parent project ("Genetic Factors in Breast Cancer: Center for Interdisciplinary Research"; PI: Dr. Dana Bovbjerg) at the Mount Sinai School of Medicine in NYC. Participants in the parent project are newly diagnosed African American breast cancer patients identified through hospitals and private specialists in NYC. These women are between 20 and 74 years of age, have a newly diagnosed primary, invasive breast cancer (Stage I, II & III), and no history of previous cancer. Each patient is recruited into the parent project approximately six months after diagnosis. In the proposed study, participants will be AAW who participated in the parent project, age 20-74 years of age and diagnosed with Stage I, II or III breast cancer. Patients will be eligible 3 months post-treatment to ensure time to adjust to survivor status. Primary treatment includes the following: unilateral mastectomy, breast conserving surgery (e.g., lumpectomy, segmental mastectomy, quadrantectomy), adjuvant radiotherapy, and adjuvant chemotherapy. Possible adjuvant hormonal therapy, not included in the definition of primary treatment, will be examined as a possible covariate. Treatment and disease stage information is collected by the parent project. Patients will be excluded if they underwent bilateral mastectomy as part of primary treatment, lack English language fluency, or do not have a working telephone number.

To provide another source of AA breast cancer patients, we will also recruit through direct referral by their physician, following identical procedures. Eligibility criteria for patients recruited through this source will be identical to those for patients recruited from the parent project, except that patient referred by physician will be no more than 4 years post-treatment.

According to power analyses (See Statistical Analyses), the proposed study requires a sample size of 300 in order achieve power of over .80 and we expect to recruit and randomize 409 participants over a 26-month period, with at least 300 participants completing the entire study based on attrition rates in previous work. This goal is eminently feasible because the parent project will recruit 800 patients over a four-year period (17 patients/month). Given the timeline of the proposed study, it is not feasible to recruit all eligible patients who participate in the parent project. Starting in Month 6, the parent project will provide the contact information of patients recruited 3-9 months earlier (119 patients) who meet eligibility requirements for the proposed study and gave permission to be contacted about other research. Starting at Month 8 and every two months until Month 30, the parent project will provide the contact information of patients recruited 3-4 months earlier (34 patients/two-month period x 12 two-month periods=408). In total, contact information for 527 patients will be available. Very few of these patients are expected to have undergone bilateral mastectomy as rates of synchronous contralateral breast cancer are low, ranging from 0.3% to 3% across several samples [50-53]. To be conservative, it is estimated that 3% (16 patients) will be ineligible due to bilateral mastectomy. Based on refusal rates reported by other interventions targeting AAW [37-40;54;55] we estimate that of the remaining 511 patients, 20% (102 patients) will refuse to participate in the randomized controlled trial and 409 patients will be randomized. In total, we expect to conduct 14 survivor surveillance intervention presentations over the course of the proposed study. Expected attrition at one-month follow-up is 5% (20 patients) based on data from several longitudinal intervention studies with African American and low-income [37;55 56]. Expected attrition at 14-month follow-up among the remaining 389 patients is an additional 20% (78 patients) based on similar studies [35;37;55]. Therefore, 311 patients are expected to complete the entire proposed study.

Procedures:

Informed Consent:

Upon first contact, if a woman agrees to participate, a research assistant will read the consent form to her. The consent form will then be sent via mail and the participant will be asked to return it via mail. The PI and research assistants will review consent with particular attention paid to pros and cons of participation. Potential subjects well be asked to verbalized their understanding of the sutdy purpose, procedures, risks and benefits as indication that they understand what involvement of the study requires.

Participants will be informed that they will be paid for each interview they complete as part of the study at the time the study is first explained and when they complete informed consent.

If a patient is identified and referred by her physician, the physician or the physician's representative will contact the patient, identified through chart review, during a regular office visit, or via a letter or telephone call in which the purpose of the study will be briefly described. They will then ask if the patient is interested in participating in the study and ask for each patient's permission to be contacted again by a project coordinator via telephone. If a potential participant expresses interest and grants permission to be contacted, the patient's name, address and telephone number will be given to the project coordinator with the proposed study. Patients will then be contacted by telephone by the research assistant who will describe study goals and discuss study procedures. The research assistant will also confirm the treatment the patient received and completion at least three months prior. Women who agree to participate will be mailed an informed consent form and asked to return it via mail. This mailing will also include ASCO surveillance recommendations to ensure that all women are exposed to this information as part of providing at least the standard of care.

Baseline Assessment: The parent project will provide the contact information of recently diagnosed patients who meet eligibility requirements for the proposed study and agree to be contacted about other research. To date, 100% of patients have given permission to be contacted again about other research opportunities. Eligible patients will then be contacted by telephone by a research assistant on the proposed study who will describe study goals and procedures. A strength of recruiting from among the "graduates" of the parent project is that demographic and medical data will be available to evaluate potential participation bias across patients whether or not they agree to participate in the proposed study. Women who agree to participate will be mailed an informed consent form and asked to return it via mail. This mailing will also include informational materials explaining ASCO surveillance guidelines to ensure that all women are exposed to this information. Once the informed consent is obtained, patients will be contacted again via telephone to complete the baseline interview assessing sociodemographic and physician information, surveillance intention and adherence, attitudinal/cognitive variables, and ethnic identity (see Instruments). For assessment of adherence, a guided recall approach will be used that includes the recollection of holidays and local events [57]. Previous projects report a 73-79% rate of agreement between self-report of mammography and medical charts in samples that included a sizable proportion of AAW [57;58] and other studies have shown a 94% rate of agreement [59]. The baseline interview will last at least 45 minutes. Prior to baseline, participants will be randomized to either the intervention condition or control condition (see descriptions below). At the end of the interview, the research assistant, who has been blind to participants' intervention assignment, will open an envelope in which subjects' assignment is indicated. Women who have been randomly assigned to the intervention condition will be offered participation in the intervention within the next 2-3 weeks. Women assigned to the control condition will be informed that they will be contacted again in 5-6 weeks for their second assessment. All women will be informed that they will receive a money order for $20 for their time in completing the baseline assessment.

Intervention Condition: One to three weeks following completion of the baseline, participants in the survivor surveillance intervention condition will attend a presentation that is grounded in the Witness model. During the first five months of proposed study, the Witness model will be tailored for breast cancer survivors and the peer interventionists (breast cancer survivors and lay health advisors) will be specifically trained by the PI. African American interventionists will serve as both "BC survivor witnesses" and lay health advisors. Witness role models (WRMs) share their own experience of cancer diagnosis, treatment, and follow-up care. The program is based, in part, on the African American cultural and spiritual practice of "witnessing" or sharing of personal stories of struggle, faith, and empowerment. WRMs also stress the importance of open dialogue about breast cancer in the community. Lay health advisors (LHAs) serve a more didactic role and provide education about breast cancer recurrence and recurrence detection.

These African American peer interventionists will be recruited from the pool available in the ongoing Witness Project of Harlem. Peer interventionists will be women who: 1) have strong interpersonal communication skills, 2) ambulatory, with no health concerns which prevent local travel, 3) are accessible by telephone, be at least 21 years old, and 4) are able to read and write. We anticipate that training will include a 4-hour group session followed by a minimum of 2 individual training sessions. Pre-tests and post-tests, as well as practical demonstrations, will be used to evaluate trainees' competence. An incentive of $25 for each interventionists for each intervention conducted. This will be made available to them through money orders presented at the time of the intervention.

Presentations will be conducted at convenient sites at or near the referring hospitals and specialists. Presentations will include: 1) an inspirational introduction, 2) testimony by the breast cancer survivor about her cancer detection, survival and the importance of regular surveillance; 3) review of breast cancer facts specific to AAW by a lay health advisor; 4) discussion of concerns and myths about breast cancer and screening/surveillance that are prevalent among AAW; 5) review of ASCO guidelines; and 6) "hands-on" BSE instruction using the "grid" method, which emphasizes examination of not only the breast but adjacent areas (e.g., chest, armpit). The program is faith-based in that it begins and ends with inspirational content which may include prayer or devotion. This is at the discretion of the interventionists. Additionally, the testimony of the breast cancer survivors may include references to their spiritual faith. The educational program will not be oriented toward a specific religion or set of spiritual beliefs but presenters may refer to their personal spiritual and religious beliefs, which are diverse.

One month following the intervention, participants will be contacted by a research assistant (blind to group assignment) who will conduct a telephone interview to assess surveillance intention and adherence and changes in attitudinal/cognitive variables (see Instruments). The interview will last approximately 30 minutes and women will receive a money order for $20 for their time. Thirteen months following the one-month follow-up assessment, women in the intervention condition will be re-contacted in order to assess surveillance intention and adherence. This assessment will last approximately 10 minutes and all will receive a money order for $20 for their time. **Control Condition**: After completion of the baseline assessment and a waiting interval matched to the timing of the intervention, women in the control condition will undergo identical assessments procedures as described above.

Instruments: The majority of the following survey instruments are standardized measures and have documented reliability and validity: Sociodemographic and Physician Information; Breast Cancer Surveillance Intention and Adherence/Physician Recommendation; Perceived Access to Health Services [14]; Perceived Social Influence to Participate in Breast Cancer Surveillance; Breast Cancer Surveillance Attitudes [21;60;61]; Behavioral Control [62]; Breast Cancer Surveillance Knowledge; Perceived Breast Cancer/Recurrence Risk [63]; Ethnic Identity [64;65].

Table 1 below presents the points of administration for all measures. Unstandardized measures will be pilot tested during the first 5 months of the proposed study.

Table 1.

Parent Project	**Time 1: Pre-intervention/Baseline**	**Time 2: Post-intervention (1 month)**	**Time 3: Post-intervention (14 months)**
	Sociodemographic and physician information		

Stage of Diagnosis/Type of Treatment/Time of Treatment	Breast cancer screening surveillance intention/adherence & physician recommendation	Breast cancer screening surveillance intention/adherence & physician recommendation	Breast cancer screening surveillance intention/adherence & physician recommendation
	Perceived social influence to participate in surveillance/norms	Perceived social influence to participate in surveillance/norms	
	Surveillance-related attitudes	Surveillance-related attitudes	
	Behavioral control	Behavioral control	
	Breast cancer surveillance knowledge	Breast cancer surveillance knowledge	
	Perceived breast cancer/recurrence risk	Perceived breast cancer/recurrence risk	
	Ethnic identity/racial pride		
	Perceived access to health care		

Potential Covariates:

Sociodemographic and Physician Information: A basic sociodemographic questionnaire will be used to assess age, marital status, parental status, education, income, health insurance status and ethnicity. This measure also asks about what type of physician the participant sees for follow-up care since completion of primary breast cancer treatment. This measure will be included at baseline assessment.

Physician Recommendation: Items assessing physician recommendation for at surveillance are included in the measure of surveillance intention and adherence administered at all three assessments.

Perceived Access to Health Services (PAHS) [14] is a 10-item scale with items that address cost, convenience and the existence of a health care provider relationship. The PAHS was administered to a sample of 352 African American women and results showed adequate internal consistency (α= .78). In the proposed research, the PAHS will be administered at field survey/baseline assessment and at the post-intervention assessment

Outcome Measures:

Breast Cancer Surveillance Intention and Adherence: This measure, which was developed by the PI and colleagues, will be used to assess actual practice of mammography, physical examination/patient history, BSE and pelvic exam. The measure also assesses intention through an item developed by Sheeran and Orbell [62]. This measure also includes items regarding physician recommendation of each screening modality. This measure will be included at all three assessments.

Mediators:

Perceived Social Influence/Group Norms to Participate in Breast Cancer Surveillance: Thirteen items were developed by the PI and colleagues, will be used to participants' perceptions of social influence from other African American women to participate in regular breast cancer surveillance, as well as perception of reference group norms regarding surveillance. This measure also includes items that assess the social influence of significant others, such as family, friends, etc. The response key is a Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). This measure will be administered at baseline and one-month post-intervention.

Breast Cancer Surveillance Attitudes: A 34-item questionnaire will be used to assess participants' attitudes about mammography and breast cancer surveillance in general. This measure was based on previous work focusing on the pros and cons of cancer screening [60;61], as well as mammogram concerns [21]and breast cancer stigma [68] . The response key is a Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). In previous work, similar measures demonstrated strong internal consistency, with Cronbach's alphas ranging from .74 - .83. This measure will be administered at baseline and one-month post-intervention follow-up.

Behavioral Control Regarding Breast Cancer Surveillance: Twelve items will be used to assess participants' sense of how easy it will be to engage in surveillance behaviors (mammography, physical exam/patient history, BSE, and pelvic exam) and how confident they are that they will do so. These items were adapted from Sheeran and Orbell [62], who report moderate internal consistency (α=.67). This measure will be administered at baseline and one-month post-intervention follow-up.

Breast Cancer Surveillance Knowledge will be assessed through a 9-item face-valid measure which assesses participants' understanding of breast cancer, issues that are relevant to breast cancer survivors, and breast cancer surveillance guidelines. Response format is "yes," "no," or "not sure."This questionnaire will be administered at baseline and at the one-month post-intervention assessment.

Perceived Breast Cancer/Recurrence Risk will be assessed through rating scales ranging from 0 to 100 that ask participants to indicate how likely it is that they will develop breast cancer again, as well as how serious they think it would be if they developed breast cancer again. This scale is adapted from Weinstein [63] who observed likelihood by severity interactions for health-protective behaviors. This measure will be administered at baseline and one-month post-intervention follow-up.

Moderators:

Ethnic Identity will be assessed by two measures. The first is a 7-item measure of racial pride and connection to other African Americans that has demonstrated strong internal consistency in African American female samples (α=.67) [64]. The second is a measure of Africentrism, developed to assess the degree to which a person adheres to values of racial unity, self-determination, and collectivism [65]. Based on administration in African American samples, Cronbach's alphas for this scale range from .74 - .82. The response key is a Likert-type scale ranging from 1 (strongly disagree) to 4(strongly agree).

In order to address exploratory hypotheses, the following measures will be added. In order to address participant burden, most of these measures will be not be a part of the research interview but participants will have the option of completing them on their own and returning via U.S. mail.

Spirituality will be assessed by an integration of items from two measures that have demonstrated strong reliability in African American female samples. The first is a measure of religiosity (α = .88) and the second is a measure of spiritual locus of control (internal vs. external) (α = .73). Three additional items will be included to

assess religious behaviors *(Participants will have the option of completing these measures independently (rather than via interview) and returning them via U.S. mail.)*

The Impact of Event Scale (IES) is commonly used to measure cancer-specific distress. These 16 items assess intrusive and avoidant stress reactions to a specific stressor, in this case, the threat of prostate cancer. Participants will be asked to rate how frequently each thought or behavior occurred during the past week. These items have demonstrated strong internal reliability in previous work (alpha=.86)

Genetic Testing Awareness and Interest will be assessed through the following five items: How much have you heard or read about genetic testing for breast cancer risk?; At the present time, how interested are you in getting genetic testing for breast cancer risk?; Now that such a test is currently available, which of the following best describes your intentions? ; Do you have any relative who has been diagnosed with breast or ovarian cancer?; Is one of these relatives diagnosed with breast or ovarian cancer your parent, your sibling or your child? *(Participants will have the option of completing these measures independently (rather than via interview) and returning them via U.S. mail.)*

The Concerns About Recurrence Scale is a 30 item structured assessment of the nature of women's fears about breast cancer recurrence. This measure has demonstrated high reliability in previous samples (alpha=.87). *(Participants will have the option of completing these measures independently (rather than via interview) and returning them via U.S. mail.)*

Medical Mistrust: Two measures will be administered to assess different aspects of medical trust and mistrust. The Group-Based Medical Mistrust Scale (GBMMS) will be used to assess suspicion of mainstream health care systems and health care professionals and the treatment provided to individuals of the respondent's ethnic or racial group. The GBMMS is a 12-item scale has demonstrated strong reliability in AA and Latino samples (α = .83). The Medical Mistrust Index (MMI) is an 11-item scale that will be administered to assess one's generalized trust in medical care. The MMI includes three subscales: competence, or the expectation that healthcare providers are adequately trained and technically proficient; control, the belief that those entrusted with one's care will not inappropriately defer to the judgement of others; and agency, or the belief that competing interests will not supercede the best interest of the patient. *(Participants will have the option of completing these measures independently (rather than via interview) and returning them via U.S. mail.)*

Participatory Decision Making will be assessed by the Control Preferences Scale (CPS). The CPS includes two sets of five statements describing possible roles in medical decision-making (active, collaborative or passive). Participants will be asked to first describe their preferred role in their medical and then asked to describe the role they believe they have in their medical care. *(Participants will have the option of completing these measures independently (rather than via interview) and returning them via U.S. mail.)*

Intervention Evaluation: A brief 14-item measure will be administered immediately after the intervention in order to assess participants evaluation of the actual intervention and the presentation of educational material.

Statistical Analyses

Preliminary Analytic Considerations: **Data Characteristics**: We will examine the distribution of each measure used in the study and make decisions regarding possible transformations required to meet the assumptions of the statistical tests that will be employed. **Identification of Covariates**: While the research design involves random assignment to intervention condition, it is still possible that screening behavior may be related to sociodemographic (e.g. age, education) and/or medical variables (e.g., type of primary treatment, physician recommendations regarding screening, health care access, etc.) whose inclusion would increase the power of the analyses. Potential covariates (using somewhat liberal p-values: $p \leq 0.15$) will be examined to determine whether they should be included in the analyses described below.

Hypothesis 1: Participants in the survivor surveillance intervention condition will report greater breast cancer surveillance intention and adherence following that intervention compared to women in the control group. **Statistical Analysis**: The first outcome measure is surveillance intention. Since intention to adhere to different screening measures may be affected by different covariates, we plan to examine each screening intention individually. A mixed linear models repeated measures design will be used (SAS PROC MIXED). In these analyses, baseline intention for each screening activity will be treated as a covariate and the grouping variable as a main effect along with other covariates identified in earlier analyses. Since adherence is a binary outcome and adherence to different screening behaviors may also involve different covariates, each screening behavior will be examined individually using a Generalized Estimating Equations (GEE) approach implemented through the SAS procedure, GENMOD. Baseline intention will be treated as one covariate and intervention group will be the main focus with adherence intention immediately after the intervention and twelve months later as the outcomes. **Power Analysis**: A case-control design by Erwin and colleagues [40] has documented significant effects ($p<.0005$) of the Witness Project on BSE and mammography among healthy AAW (See Background). For purposes of power in this study, we will assume similar changes in our intervention and control groups. The effect sizes for differences in proportions are in the moderate range. With an N = 300, alpha = 0.01, power is expected to be 90% - 95%.

Hypothesis 2: The impact of the intervention on surveillance intention and adherence will be mediated by changes in attitudinal and cognitive variables (breast cancer surveillance-related social influence, attitudes, behavioral control, knowledge and perceived breast cancer risk). **Statistical Analysis**: This hypothesis is concerned with mediating mechanisms and will be tested following Baron and Kenny's recommendations [66]. Since there are repeated measures, each step will involve a mixed linear model (SAS PROC MIXED) with appropriate covariates. The following hypotheses will be evaluated: 1) intention and adherence following the intervention and 14 months later will be compared to the control group with baseline data as covariates; 2) participants will have greater changes in attitudinal/cognitive variables following the intervention and 14 months later compared to the control group with baseline attitudes and cognitions as covariates; and 3) attitudinal/cognitive variables will be related to intention and adherence immediately after the intervention and 14 months later with appropriate baseline information included as covariates. Assuming the Baron and Kenny criteria [66] have been met, the mediating variable (attitudinal/cognitive variables) will be entered into the equation predicting each outcome (intention and adherence immediately after the intervention and 14 months later). If mediation occurs, the parameter estimate for group will no longer be significant. We shall test the significance of the mediating effect using a procedure described by Baron and Kenny [66]. **Power Analysis**: Since this hypothesis is concerned with mediating processes, a discussion of power is not relevant.

Exploratory Hypothesis 1: Ethnic identity will moderate the impact of the intervention such that women with stronger ethnic identity will benefit most from the intervention. We anticipate that the individual difference variables act as moderators of the effectiveness of the intervention such that breast cancer surveillance intention and adherence will vary at different levels (e.g., weak ethnic identity vs. low ethnic identity). **Statistical Analysis**: If such moderator effects are present, they should operate as interactions between the pre- and post-intervention time period. Because the possible interactive effects of each of these individual difference variables may be obscured if all interaction terms are included in a single model, we will first examine the effects of each of these individual difference variables on breast cancer screening outcomes graphically, grouping first by baseline, immediately after the intervention, and at the 14 month follow-up. This preliminary examination may provide guides as to which of the two individual difference variables is the most likely candidate for interaction effects. Based on the graphical results, we shall enter the interaction terms sequentially using the approach described in Primary Hypothesis 1.

Risks/Benefits Assessment

Potential risks of participation in psychosocial research include emotional discomfort or distress that might result from being asked about personal cancer risk or recurrence risk during assessments. The interviewers will be trained to remind participants of the voluntary nature of the research and that participants have the right to refuse to answer specific questions and may stop at any time for any reason. The interviewers will

also be able to contact the clinical psychologists associated with the project and be able to provide referrals if necessary. The alternative procedure would be non-participation in the research component. Potential benefits include learning more about breast cancer surveillance recommendations for breast cancer survivors. It is believed that the benefits outweigh the risks.

Disposition of Data

The proposed study will provide for the same level of confidentiality as is standard with medical information. All participants will be assigned a numeric code so they cannot be identified in study data analyses, publications, and presentations. Research records will be kept in locked and secured files. Only the PI and individuals who are assisting with this project will have access to these records. A cross-referenced file that will link numeric codes with participants' consent forms will be secured by the PI. Data will be entered into a computer database that is saved on a computer disk rather than a computer hard drive. This disk will be secured by the PI.

Adverse Events

In the proposed study, an adverse event will be defined as the occurrence of significant emotional distress that results from being asked about personal cancer risk or recurrence risk during assessments. If such an adverse event should occur, the interviewer conducting the assessment will contact the PI, who is a licensed clinical psychologist who will conduct a brief psychological assessment and refer the participant to appropriate psychological care. Adverse experiences that are both serious and unexpected will be immediately reported by telephone to the USAMRMC, Deputy of Regulatory Compliance and Quality and by facsimile. A written report will follow the initial telephone call within 3 working days. The same procedure will be followed in reporting the adverse event to the Institutional Review Board of Mount Sinai School of Medicine where the research is being conducted.

Modification or Amendments to Protocol

Any and all modifications or amendments to the protocol will be submitted to the Institutional Review Board of Mount Sinai School of Medicine for review and approval, and the HSRRB for second level review and approval. The same procedure will be followed if the study is terminated before completion.

Departure from Protocol

Any departure from the protocol will noted in participant records and notification will be sent to the Institutional Review Board of Mount Sinai School of Medicine, as well as the HSRRB.

Principal Investigator:

Hayley Thompson, Ph.D. is an instructor at the Derald Ruttenberg Cancer Center at Mount Sinai School of Medicine. Dr. Thompson will be responsible for all aspects of the research protocol. Dr. Thompson has extensive experience working with African Americans in the development and coordination of culturally relevant programming, the exploration of sociocultural factors and health outcomes, and conducting health-related psychosocial assessments. She also has experience in research project management. In addition, she is Training Coordinator for The Witness Project® of Harlem (WPH). This experience will enable her to develop training tools for women who will be implementing the survivor surveillance intervention described in the proposed study. Dr. Thompson will also conduct the actual training sessions. She will also directly supervise intervention delivery and attend all intervention presentations. Dr. Thompson will supervise the research assistant in subject recruitment, administration of questionnaires, and other support tasks. She will also supervise the data entry clerk. Dr. Thompson will also establish quality control checks and design monthly reports on recruitment and

follow-up. Dr. Thompson will work closely with Drs. Valdimarsdottir, Winkel and Bovbjerg and Ms. Jandorf on data analysis and preparation of results for presentations and publications. Her time commitment will be 30% on all years of the study.

Co-Investigators:

Heiddis Valdimarsdottir, Ph.D. will serve as a co-investigator. Dr. Valdimarsdottir is an assistant professor at the Derald Ruttenberg Cancer Center at Mount Sinai School of Medicine and has worked closely with Dr. Thompson on the development of culturally-tailored interventions targeting African American women at increased genetic risk for breast cancer. Dr. Valdimarsdottir is currently the Principal Investigator of the Department of Defense-funded project, "Impact of Culturally Tailored Counseling on Psychobehavioral Outcomes and BRCA Decision Making Among Women with Breast Cancer" and has extensive experience in the psychological evaluation of individuals at familial risk for breast cancer. In terms of the proposed study, Dr. Valdimarsdottir will work with Dr. Thompson to develop the content of the survivor surveillance intervention, as well as to pilot test and refine measures. Dr. Valdimarsdottir's time involvement will be 10%.

Lina Jandorf, M.A. will serve as a co-investigator. Ms. Jandorf is a research assistant professor and Outreach Director at the Derald Ruttenberg Cancer Center. Ms. Jandorf is Project Coordinator of the Witness Project of Harlem and is also responsible for all aspects of outreach, recruitment and interviewing as the head of recruitment core of the Department of Defense-funded project, "Genetic Factors in Breast Cancer: Center for Interdisciplinary Research," which will recruit 800 African American breast cancer patients over a four-year period. She will assist Dr. Thompson in maximizing participant recruitment and will work with Dr. Thompson to develop training tools to develop training tools to educate peer interventionists. Her time commitment will be 5% during all years of the study.

Dana Bovbjerg, Ph.D. will serve as a co-investigator. Dr. Bovbjerg is the head of Biobehavioral Medicine Program at the Derald Ruttenberg Cancer Center at the Mount Sinai School of Medicine. He is also principal investigator for the Department of Defense-funded project, "Genetic Factors in Breast Cancer: Center for Interdisciplinary Research," the parent program from which participants will be recruited for the proposed study. Dr. Bovbjerg has expertise in the investigation of biobehavioral consequences of stress in several populations, including healthy volunteers, individuals at high risk for cancer, and cancer patients. Dr. Bovbjerg will work closely with Dr. Thompson in the implementation of the proposed study and collaborate directly with Dr. Thompson on all aspects of the research design as well as contribute to data analysis and the preparation of manuscripts. His time commitment will be 2.5 % during all years of the study.

Other Personnel:

Research Assistant TBN (100%): A research assistant will be hired to recruit participants, conduct baseline and follow-up interviews, manage a tracking system for the multiple assessments, perform basic data management and oversee the mailing of participant incentives. This full-time research assistant will also be responsible for the scheduling and coordination of survivor surveillance intervention presentations and will assist with peer interventionist training. This research assistant will attend intervention presentations along with Dr. Thompson to record the attendance of study participants and maintain the integrity of the randomized controlled trial. This program coordinator will have 100% involvement for all years of the study.

Data Entry Clerk TBN: An assistant will be hired to enter baseline and post-intervention data as well as basic data management. The time commitment for the data entry clerk will be 25% for the first 3 years of study.

Consultants:

Deborah Erwin, Ph.D. is an associate professor at the University of Arkansas Medical School, Division of Surgical Oncology. She is the co-founder of the Witness Project and is the Principal Investigator the project entitled AReplication and Dissemination of the Witness Project@ funded by the Centers for Disease Control. Dr. Erwin will work with Dr. Thompson to develop training tools to educate peer interventionists. Dr. Erwin will also work with Dr. Thompson to refine measures and assessment strategies. Dr. Erwin will be paid at a rate of $700 per day (7 days in Year 1 = $4900) in addition to the costs of her transportation to and accommodations and amenities in New York City ($1600).

Gary Winkel, Ph.D. is a professor at the City University of New York. He has provided statistical expertise and consultation with psychosocial investigators at the Derald Ruttenberg Cancer Center for six years. Dr. Winkel's statistical expertise is in regression strategies as well as methods of analyzing longitudinal data with missing data. He teaches several graduate level statistics courses, including structural equation modeling and regression. He will work closely with Dr. Thompson in all aspects of the data interpretation. He is extremely well-qualified and familiar with the study design and methods to be used in the proposed research. Dr. Winkel will be paid at a rate of $100 per hour (30 hours in Year 3; 30 hours in Year 4).

Draft of a study introduction letter to participants recruited from parent research project at Mount Sinai School of Medicine

We would like to invite you to participate in an exciting project. This project is a research study evaluating ***Survivors in Spirit*** (SIS) program developed to educate Black breast cancer survivors about the follow-up care that is recommended once breast cancer treatment is over. ***Survivors in Spirit*** programs are conducted by Black breast cancer survivors and other women who volunteer their time to spread the word about the follow-up care.

We are contacting you because you participated in the Tri-State Women's Circle of Health study and were interviewed by **(name of interviewer)** on **(date)**. At that time you stated that you were willing to be contacted about other research projects.

What will it mean if you participate in this research study?

1. You will be interviewed by one of our staff over the telephone. This will take about 45 minutes.
2. You will be invited to attend a ***Survivors in Spirit*** program in the near future or after your participation in the study is over (in about 1 year). Whether or not you are invited in the near future or later is based on random assignment (like the flip of a coin). If you are invited to a program you can be compensated for transportation costs.
3. One month later, you will be interviewed by one of our staff over the telephone. This interview will take about 30 minutes.
4. One year later, you will be interviewed one last time by one of our staff. This interview will be about 15 minutes.

You will be sent a money order for $20.00 for every interview you complete.

Enclosed you will find a brochure regarding the study. One of our staff will be contacting you by telephone to give you more information and to answer any questions you may have. If you wish you may contact us. Please call Monique Littles, Project Coordinator for ***SIS*** at (212) 659-5477 or email: monique.littles@mssm.edu. Thank you.

Sincerely,

Hayley Thompson, Ph.D.
Principal Investigator for ***SIS***
Assistant Professor
Mount Sinai School of Medicine

Monique Littles, MA
Project Coordinator for ***SIS***

Draft of a study introduction letter to participants recruited through referring physicians (sent from physician on their letterhead)

We would like to invite you to participate in an exciting project. This project is a research study evaluating ***Survivors in Spirit*** (SIS) a program developed to educate Black breast cancer survivors about the follow-up care that is recommended once breast cancer treatment is over. ***Survivors in Spirit*** programs are conducted by Black breast cancer survivors and other women who volunteer their time to spread the word about the follow-up care.

We are contacting you about this study because it is between 3 months and 4 years since you completed breast cancer treatment.

What will it mean if you participate in this research study?

1. You will be interviewed by one of our staff over the telephone. This will take about 45 minutes.
2. You will be invited to attend a ***Survivors in Spirit*** program in the near future or after your participation in the study is over (in about 1 year). Whether or not you are invited in the near future or later is based on random assignment (like the flip of a coin). If you are invited to a program you can be compensated for transportation costs.
3. One month later, you will be interviewed by one of our staff over the telephone. This interview will take about 30 minutes.
4. One year later, you will be interviewed one last time by one of our staff. This interview will be about 15 minutes.

You will be sent a money order for $20.00 for every interview you complete.

Enclosed you will find a brochure regarding the study. One of our staff will be contacting you by telephone to give you more information and to answer any questions you may have. If you wish you may contact us at [name and telephone number of hospital/clinic].

Sincerely,

Survivors in Spirit **Research Team**

(left to right:: Dr. Hayley Thompson, Principal Investigator, Mount Sinai School of Medicine, Monique Littles, MA, Project Coordinator for ***SIS***, Nikisha Williams, MS, Clinical Research Coordinator)

"Women Who Look Ahead" was used with the permission of the artist, Monica Stewart.

Survivors in Spirit (SIS)
C/O Monique Littles, MA
Mount Sinai School of Medicine
Department of Oncological Sciences
One Gustav L. Levy Place
Box 1130
New York, NY 10029
Phone: 212-659-5477
Fax: 212-849-2564

Mount Sinai School of Medicine GCO #02-0561 (01)

SIS Advisory Board

Eloise Nobles, Witness Role Model, Witness Project of Harlem

Desiree Walker, Witness Role Model, Witness Project of Harlem

Helen Webber, Witness Role Model, Witness Project of Harlem

Marilyn Moore, Executive Director, Witness Project of Connecticut

Stephanie Billingsley, Witness Role Model, Wtness Project of Harlem

Elizabeth Carde, Lay Health Advisor, Witness Project of Harlem

Susan H. Lee, MD, Breast Surgeon, New York Hospital Queens Breast Center

Dorothy Burch, RN, MS

Alberta Morgan, Lay Health Advisor, Witness Project of Harlem

Reather McAllister, Witness Role Model, Witness Project of Harlem

Jenny Romero, MD, Oncologist, Ralph Lauren Center for Cancer Care/Prevention

Erica Wahl, MS, CGC, Genetic Counselor, Dept. of Oncological Sciences, Mount Sinai School of Medicine

Lina Jandorf, Assistant Research Professor, Dept. of Oncological Sciences, Mount Sinai School of Medicine

Bert Petersen, Jr., MD, Surgical Oncologist, Beth Israel Medical Center

Vannisha Taylor, Witness Role Model, Witness Project of Harlem

Deborah Bristol, Breast Cancer Program Coordinator, Kings County Hospital

SURVIVORS IN SPIRIT

(SIS)

Looking Ahead to Life After Breast Cancer Treatment

What is Survivors in Spirit (SIS)?

Survivors in Spirit (SIS) is a faith-based educational program focusing on Black breast cancer survivors and the cancer surveillance, or follow – up care, that is recommended after the completion of primary treatment for breast cancer.

SIS is part of a research study funded by the Department of Defense Breast Cancer Research Program and directed by Hayley Thompson, Ph.D. at Mount Sinai School of Medicine. This study is also being conducted at New York Hospital Queens (Dr. Susan Lee, PI) and Kings County Hospital (Deborah Bristol, PI).

Why was *SIS* developed?

Breast cancer survivors are a high-risk group. A breast cancer survivor is at considerable risk of breast cancer recurrence (developing breast cancer again) and is 3 times as likely to develop a new breast cancer compared to a woman who has never had breast cancer.

Regular follow-up care and screening can find breast cancer at an early stage when it is more treatable and better controlled.

Help us learn how well SIS works

We hope that you will participate in this research study to help us learn if SIS is an effective educational program.

What will it mean if you participate in this research study?

1. You will be interviewed by one of our staff over the telephone. This will take about 45 minutes.

2. You will be invited to attend a **SIS** program in the near future or after your participation in the study is over (in about 1 year). Whether or not you are invited in the near future or later is based on random assignment (like the flip of a coin).

3. One month later, you will be interviewed again over the telephone. This interview will take about 30 minutes.

4. About one year later, you will be interviewed one last time by one of our staff. This interview will be about 15 minutes.

You will be sent a money order for $20.00 for every interview you complete.

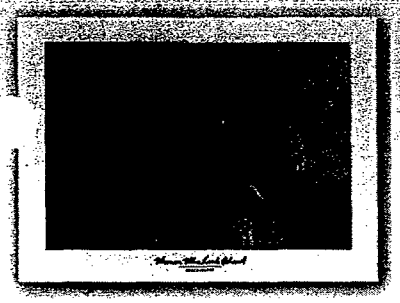
What will happen at a *SIS* program?

SIS programs are conducted by two types of volunteers.

You will hear from breast cancer survivors who share their personal treatment, and follow-up care. These survivors will also share the role that spiritual faith had in their cancer experience and in their lives in general.

You will also hear from lay health educators who teach the facts about breast cancer recurrence and inform survivors about the guidelines for follow-care.

If you are interested in participating in this research study, contact Monique Littles, Project Coordinator, at 212-659-5477 (e-mail: monique.littles @mssm.edu) for more information. You may also contact, Hayley Thompson, Ph.D., Principal Investigator, at 212-659-5648 (email: hayley.thompson @ mssm.edu).



Survivors in Spirit Recruitment Script

I. Greeting and introduction to *Survivors in Spirit* (SIS)

Hello.

I am calling today to invite you to participate in *Survivors in Spirit. Survivors in Spirit* is a research study directed by Dr. Hayley Thompson here at Mount Sinai School of Medicine.

Do you have a few minutes to talk about *Survivors in Spirit*?

If yes, continue. If no, schedule another time to speak. If woman is not interested, go to intake form.

Survivors in Spirit is a faith-based educational program focusing on Black breast cancer survivors and the follow –up care, that is recommended after the completion of primary treatment for breast cancer. During a *Survivors in Spirit* program, you will hear from breast cancer survivors who share their personal stories of cancer diagnosis, treatment, and follow-up care. These survivors will also share the role that spiritual faith had in their cancer experience and in their lives in general. You will also hear from lay health educators who teach the facts about breast cancer recurrence and inform survivors about the guidelines for follow- up care after treatment.

If you choose to participate in *Survivors in Spirit* .

- You will be invited to attend a *Survivors in Spirit* program in the near future or after your participation in this study is over (in about 1 year). Whether or not you are invited in the near future or later is based on random assignment (like the flip of a coin).
- You will be interviewed over the telephone 3 times over the course of a year.
- You will be sent a money order for $20.00 for every interview you complete.

II. Obtain verbal consent and collect study intake information

A) Are you interested in participating in the **SIS** study?
[If yes, continue to (B) below. If no, check the "NO" box on the study intake form, complete questions about why survivor does not want to participate in study, and end the call.]

B) Now that you have agreed to participate in the study I need to ask you a few questions. ***[Ask the questions on the intake sheet.]***

III. Emphasize importance of being willing to attend the intervention and explain the consent/HIPAA form

A) I just need to discuss one more thing with you. You may be invited to a *Survivors in Spirit* program in the near future. If you are, it is very important that you are available and willing to attend the program. If, for any reason, you think you may not want to attend a program, or will not be able to attend a program please let me know. [Make any notes about this on the intake sheet.]

B) Thank you again for agreeing to participant in **SIS**. In the next couple of days, you will receive two forms in the mail that you will need to complete and return before your first interview. The first is a consent form that indicates that you understand what the study entails. The second is a HIPAA form, which discusses the privacy of the information you give to us. Please know any information you provide is confidential.

GCO #02-0561 (01)

***Survivors in Spirit* Study Intake Sheet**

Date: _____

Participant ID: _____ **Participant Name:** _____

Home phone_____ **Work phone**_____ **Other** _____

1. Agreed to participate? ☐YES ☐NO

If no, go to question 2 and complete call. If yes, go to question 3.

---

2. May I ask why you do not wish to participate?

☐ Not interested
☐ No time/too busy
☐ Feel burdened by research studies
☐ Not available on dates of SIS programs
☐ Other _____

****[DO NOT READ: A woman is ineligible if***

- ***It has been less than 3 months since completion of <u>all</u> primary treatment (surgery, radiotherapy, chemo)***
- ***she has had a double mastectomy***
- ***she has been diagnosed with breast cancer again since the participating in parent project.***
- ***she was diagnosed with any cancer before participation in parent project]*****

3. Were you ever diagnosed with any cancer before your breast cancer? ☐YES ☐NO
If yes, read ineligibility paragraph on page 3.

4. Have you been diagnosed with breast cancer again since your first diagnosis? ☐*YES* ☐*NO*
If yes, read ineligibility paragraph on page 3.

5. What type of treatment did you receive for your breast cancer? ***<u>Read all options</u>.***

a. Mastectomy ☐YES ☐NO
Approximate date of surgery _____
At least 3 months ago? ☐YES ☐NO ***If no, read ineligibility paragraph on page 3.***

i. Double mastectomy? ☐YES ☐NO ***If yes, read ineligibility paragraph on page 3***

b. Breast Conserving (Lumpectomy, segmental mastectomy, quadranectomy, etc.) ☐YES ☐NO
Approximate date of surgery _____
At least 3 months ago? ☐YES ☐NO ***If no, read ineligibility paragraph on page 3.***

c. Radiation therapy ☐YES ☐NO
If yes, when did radiation therapy end? (month/year) _____
At least 3 months ago? ☐YES ☐NO ***If no, read ineligibility paragraph on page 3.***

d. Chemotherapy? ☐YES ☐NO
If yes, when did chemotherapy end? (month/year) _____
At least 3 months ago? ☐YES ☐NO ***If no, read ineligibility paragraph on page 3.***

e. Hormonal therapy (Tamoxifen, etc.)? ***This is not part of primary treatment and not relevant to eligibility.*** ☐YES ☐NO

6. What days and times are best for you to attend a Survivors in Spirit program? _____

---

6. Would receiving Metrocard or some other type of assistance with transportation make it easier for you to participate in a Survivors in Spirit program?

☐YES ☐NO

7. Would providing free childcare make it easier for you to participate in an intervention program?

☐YES ☐NO

9. When may I schedule your first interview?

Remind participant that we must receive their consent & HIPAA forms before we can interview her.

RETURN TO SCRIPT

In case of ineligibility, check this box ☐ ***and read the following :***

I'm sorry, but because of ***[exclusion criteria]***, you are not eligible for this study. However, you are welcome to attend one of the Survivors in Spirit programs I mentioned. Are you interested in attending?
☐YES ☐NO

If yes: We will send you an invitation.
If no: Okay. Again, I'm sorry and thank you so much for your time.

Draft of consent cover letter for all women who agree to be in the study

I called you on _____ and at that time, you agreed to participate in a research study to evaluate a program that educates Black breast cancer survivors about follow-up care after treatment.

Enclosed are forms that you will need to complete and return to us (a self-addressed stamped envelope is also enclosed). The forms include:

- 2 consent forms (1 to send back, 1 for you to keep for your records)
- 2 HIPPA forms (1 to send back, 1 for you to keep for your records)
- A questionnaire

All the forms include instructions or notes that will guide you in completing them. Please return one consent form and one HIPPA form. **Please do not return the questionnaire or fill out the questionnaire. We have sent you the questionnaire so you can read along during the telephone interview.** In about 1 week, I will call you to answer any questions you have about the forms and the study.

Please remember:

- Your participation is voluntary
- If you decide not to participate it will not affect your medical care in any way
- All information is **CONFIDENTIAL**

If you have any questions, feel free to call me at (212) 659-5477 or email: monique.littles@mssm.edu.

Sincerely,

Monique Littles, M.A.
Project Coordinator for ***SIS***
Department of Oncological Sciences
Mount Sinai School of Medicine

Cover letter for part II of the questionnaire for all women who agreed to be in the study

May 26, 2005

Dear Ms.,

Thank you for completing Part I of your first interview for ***Survivors in Spirit***. Part II of the interview is enclosed with this letter. Please complete this questionnaire on your own. The questionnaire has 4 sections and should take about 20 minutes to complete.

When you have completed the questionnaire please return it using the pre-addressed stamped envelope that is included with this letter. If you have any questions, feel free to contact project coordinator Monique Littles at 212-659-5477 or project coordinator Nikisha Williams at 212-659-5647.

Thank you again for agreeing to participate in ***SIS***. Your time and effort is greatly appreciated.

Sincerely,

Monique Littles, M.A.
Project Coordinator for ***SIS***
Department of Oncological Sciences
Mount Sinai School of Medicine

Nikisha Williams, M.A.
Project Coordinator for ***SIS***
Department of Oncological Sciences
Mount Sinai School of Medicine

Time 2 cover letter for all women who agreed to be in the study

Dear Ms. (participant last name),

You recently agreed to participate in ***Survivors in Spirit***, a research study to evaluate a program that educates Black breast cancer survivors about follow-up care after treatment. We have already interviewed you once on (Day and Date) and it is now time for your second interview.

Your second interview is scheduled for (Day and Date). Enclosed is a copy of the questionnaire that will be used during you interview. **Please do not return the questionnaire or fill out the questionnaire. We have sent you the questionnaire so you can read along during the telephone interview.**

Please remember:

- Your participation is voluntary
- If you decide not to participate it will not affect your medical care in any way
- All information is **CONFIDENTIAL**

If you have any questions, feel free to call me at (212) 659-5477 or email: monique.littles@mssm.edu.

Sincerely,

Monique Littles, M.A.
Project Coordinator for ***SIS***
Department of Oncological Sciences
Mount Sinai School of Medicine

Questionnaire 1 – Part 1

Thank you for participating in our study of Survivors in Spirit!

Remember:

- Do not complete this questionnaire until your scheduled telephone interview.
- The questionnaire is for you to read while you are being interviewed.
- All the information is confidential and private.

Last updated 4/8/05, 1:43 PM (HT)

Section 1:

1. What is your date of birth? ____/____/____ What is your age?_____ years of age

2. Are you
   - ☐ Currently married
   - ☐ Currently living with partner
   - ☐ Separated
   - ☐ Divorced
   - ☐ Widowed
   - ☐ Never married

3a. Do you have any children? ☐ Yes ☐ No If yes, how many? _____

3b. Do you have any daughters age 18 or older? ☐ Yes ☐ No If yes, how many? _____

4. Are you currently employed? ☐ Yes ☐ No

5. What is the highest level of education that you completed?
   - ☐ Less than 8th grade
   - ☐ 8th to 11th grades
   - ☐ High School graduate
   - ☐ Some college or university
   - ☐ Vocational or technical school
   - ☐ Bachelor's Degree
   - ☐ Graduate Degree

6. What is the estimated total income for your household for the past year, before taxes, from all sources?
   - ☐ Less than $10,000
   - ☐ $10,000 to $19,999
   - ☐ $20,000 to $39,999
   - ☐ $40,000 to $$59,999
   - ☐ $60,000 to $100,000
   - ☐ More than $100,000

7. How many people are supported by this income? _____

8. Which of the following best describes you? Choose as many that apply.

   ☐ Black-American/African American
   ☐ Afro-Caribbean/West Indian
   Which ethnic group (i.e. Jamaican, Guyanese)?_____
   ☐ African
   Which ethnic group (i.e. Igbo, Yoruba)? _____
   ☐ Afro-Latina
   Which group (i.e., Puerto Rican, Dominican)? _____
   ☐ Other_____

9. In which country were you born?
   (Please indicate which state if born in US.) _____

10. How many years have you lived in the US? _____ years _____ months

11. Do you live continuously in the US (at least 8 months out of the year)? ☐ Yes ☐ No

12. Which religion do you identify with, if any?

- ☐ Catholic
- ☐ Protestant (i.e. Lutheran, Baptist, Methodist)
- ☐ Jewish
- ☐ Muslim
- ☐ Hindu
- ☐ Buddhist
- ☐ None
- ☐ Don't know
- ☐ Other: please specify

_____

13. What type of health insurance do you have? Choose as many that apply.

- ☐ Medicaid
- ☐ Medicare
- ☐ Employer-provided insurance (like Oxford, Blue Cross/Blue Shield, HIP)
- ☐ Pay for insurance out-of-pocket
- ☐ I do not have health insurance (pay out of pocket for health care)
- ☐ Other _____
- ☐ Don't know

13. When were you first diagnosed with breast cancer (month/year): _____

14. Breast cancer diagnosed in one or both breasts? . One . Both

15. What type of treatment did you receive for your breast cancer?

a. Mastectomy (total removal of the breast) . Yes . No Date of surgery _____

b. Breast conserving surgery (partial removal of the breast) . Yes . No Date of surgery _____

c. Radiation therapy . Yes . No When did radiation end? _____

d. Chemotherapy . Yes . No When did chemotherapy end? _____

e. Hormonal therapy (Tamoxifen, etc.) . Yes . No When did hormonal therapy end? _____

16a. Were you diagnosed with breast cancer again after the first diagnosis ? . Yes . No

b. Were you diagnosed with any cancer after the first breast cancer diagnosis ? . Yes . No

17. What type of doctor do you see for follow-up care since you have completed your breast cancer treatment? **You may indicate more than one type of doctor.**

☐ Surgeon (doctor who performed surgery on your breast to treat the cancer)

☐ Male ☐ Female Estimated ethnicity/race _____

☐ Radiation oncologist (doctor who specializes in radiation to treat breast cancer)

☐ Male ☐ Female Estimated ethnicity/race _____

☐ Medical oncologist (doctor who uses chemotherapy, hormone therapy and other medications to treat cancer)

☐ Male ☐ Female Estimated ethnicity/race _____

☐ Primary care physician (doctor who is trained to give you basic care. This is often a family physician or internist.)

☐ Male ☐ Female Estimated ethnicity/race _____

☐ Gynecologist (doctor who specializes in treating diseases of the female reproductive organs, or the parts of the body related to having sex and having a baby)

☐ Male ☐ Female Estimated ethnicity/race _____

☐ Other _____

☐ Male ☐ Female Estimated ethnicity/race _____

18. How much do you agree with the following statement?

"Overall, I am satisfied with my follow-up care I have received since completing breast cancer treatment."

- □ Strongly Agree
- □ Agree
- □ Not Sure/ Undecided
- □ Disagree
- □ Strongly Disagree

19. Have you had any relatives or family members who have had cancer?

☐ Yes ☐ No

Please list any relatives or family members who have had cancer. If a family member had more than one type of cancer, please list them twice. If a family member had breast cancer, please indicate whether one or both breasts were affected.

Family Member (e.g. grandmother, aunt)	***Paternal or Maternal***	*Type or Location of Cancer (e.g. breast, prostate)*	*Age at Diagnosis*	*Did this person die from cancer?*
	☐ *P* ☐ *M*			☐ *Yes* ☐ *No*
	☐ *P* ☐ *M*			☐ *Yes* ☐ *No*
	☐ *P* ☐ *M*			☐ *Yes* ☐ *No*
	☐ *P* ☐ *M*			☐ *Yes* ☐ *No*
	☐ *P* ☐ *M*			☐ *Yes* ☐ *No*
	☐ *P* ☐ *M*			☐ *Yes* ☐ *No*

20. Have you ever had any of the following medical conditions?

(Check one box on each line)

a. Some other type of cancer before your breast cancer If yes, what type? _____ When were you diagnosed? _____	☐ Yes	☐ No
b. Diabetes	☐ Yes	☐ No
c. Heart attack, chest pain	☐ Yes	☐ No
d. Stroke	☐ Yes	☐ No
e. Amputation	☐ Yes	☐ No
f. Circulation problems in your legs or feet	☐ Yes	☐ No
g. Asthma, emphysema, breathing problems	☐ Yes	☐ No
h. Stomach ulcer, irritable bowel	☐ Yes	☐ No
i. Kidney disease	☐ Yes	☐ No
j. Major depression	☐ Yes	☐ No
k. Seizures	☐ Yes	☐ No
l. Alcoholism or alcohol problems	☐ Yes	☐ No
m. Drug Problems	☐ Yes	☐ No
n. Current or past cigarette smoker	☐ Yes	☐ No

Section 2

1. Since you completed breast cancer treatment, has your doctor recommended that you have mammogram?

☐Yes ☐No ☐Not sure

2. Since you completed breast cancer treatment, have you had a mammogram?

☐Yes ☐No ☐Not sure

3. Since you completed breast cancer treatment, how many mammograms have you had in total?

☐None ☐1 ☐2 ☐3 ☐4 ☐5 or more

4. Were any of these mammograms <u>not</u> routine (you had it because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

5. How many mammograms have you had in the past 12 months?

☐None ☐1 ☐2 ☐3 or more

6a. When was the date of your last mammogram? Date_____

☐Within the past 6 months
☐Between 7 – 12 months ago
☐Between 13 – 18 months ago
☐Between 19 – 24 months ago
☐More than 24 months ago
☐Not sure

6b. When was the date of the mammogram before the one in 6a? Date_____

☐ 6 months before
☐Between 7 – 12 months before
☐Between 13– 18 months before
☐Between 19 – 24 months before
☐More than 24 months before
☐Not sure

7. Do you have an appointment to have a mammogram?

☐I have an appointment When? _____
☐I have tried to make an appointment recently but I do not have one
☐I have no appointment

Section 2A

The interviewer will let you know if you need to answer the questions on this page.

8a. How much do you agree or disagree with this statement: "I intend to have a mammogram at least 12 months from the date of my last mammogram."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

9a. How much control do you have over getting a mammogram at least 12 months from the date of your last mammogram?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

10a. Having a mammogram at least 12 months from the date of your last mammogram will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

11a. Please tell me how much you agree or disagree with the following statements. Do you think that having a mammogram at least 12 months from the date of your last mammogram would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

12a. Most people who are important to you think you should have a mammogram at least 12 months from your last one.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2B

The interviewer will let you know if you need to answer the questions on this page.

8b. How much do you agree or disagree with this statement: "I intend to have a mammogram sometime in the next 12 months."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

9b. How much control do you have over getting a mammogram sometime in the next 12 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

10b. Having a mammogram sometime in the next 12 months will be ….

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

11b. Please tell me how much you agree or disagree with the following statements. Do you think that getting a mammogram in the next 12 months would be….

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

12b. Most people who are important to you think you should have a mammogram sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3

1. Since you completed breast cancer treatment, has your doctor recommended that you have a physical examination (physical examination is an evaluation of the body and its functions using inspection, feeling with the hands, tapping with the fingers, and listening)?

☐Yes ☐No ☐Not sure

2. Since you completed breast cancer treatment, have you had a physical examination?

☐Yes ☐No ☐Not sure

3. What type of doctor have you seen for a physical examination? **You may indicate more than one type of doctor.**

☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

4. Since you completed breast cancer treatment, how many physical examinations have you had in total?

☐None ☐1-3 ☐ 4-6 ☐7-9 ☐ 10 or more

5. Were any of these examinations <u>not</u> routine (you went because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

6. How many physical examinations have you had in the past 12 months?

☐None ☐1 ☐2 ☐3 or more

7. When was the date of your last physical examination? Date_____

☐Within the past 3 months
☐Between 4- 6 months ago
☐Between 7 – 12 months ago
☐More than 12 months ago
☐Not sure

8. Do you have an appointment to have a physical examination and discuss any symptoms you might have?

☐ I have an appointment When? _____

☐ I have tried to make an appointment recently but I do not have one

☐ I have no appointment

Section 3A

The interviewer will let you know if you need to answer the questions on this page.

9a. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 6 months from the date of my last exam."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

10a. How much control do you have over having a physical examination at least 6 months from the date of your last exam?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11a. Having a physical examination at least 6 months from the date of your last exam will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

2a. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 6 months from the date of your last exam would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13a. Most people who are important to you think you should have a physical examination at least 6 months from the date of your last exam.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3B

The interviewer will let you know if you need to answer the questions on this page.

9b. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 6 months."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

10b. How much control do you have over having a physical examination sometime in the next 6 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11b. Having a physical examination sometime in the next 6 months will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

12b. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination sometime in the next 6 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13b. Most people who are important to you think you should have a physical examination sometime in the next 6 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3C

The interviewer will let you know if you need to answer the questions on this page.

9c. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 12 months from the date of my last exam."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

10c. How much control do you have over having a physical examination at least 12 months from the date of your last one?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11c. Having a physical examination at least 12 months from the date of your last one will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

12c. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 12 months from the date of your last one would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13c. Most people who are important to you think you should have a physical examination at least 12 months from the date of your last one.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3D

The interviewer will let you know if you need to answer the questions on this page.

9d. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 12 months."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

10d. How much control do you have over having a physical examination sometime in the next 12 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11d. Having a physical examination sometime in the next 12 months will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

12d. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination sometime in the next 12 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

13d. Most people who are important to you think you should have a physical examination sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 4

1. Since you completed breast cancer treatment, has your doctor recommended that you see a doctor who can ask you about symptoms or problems related to breast cancer?

☐Yes ☐No ☐Not sure

2. Since you completed breast cancer treatment, has a doctor asked you about any symptoms or problems related to breast cancer?

☐Yes ☐No ☐Not sure

3. What type of doctor asked you about symptoms or problems? **You may indicate more than one type of doctor.**

☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

4. Since you completed breast cancer treatment, how many times has a doctor asked you about symptoms or problems related to breast cancer, in total ?

☐None ☐1-3 ☐ 4-6 ☐7-9 ☐ 10 or more

5. Were any of these discussions <u>not</u> routine (you had the discussion because you had specific symptoms or problems)?

☐Yes ☐No ☐Not sure

6. How many times has a doctor asked you about symptoms or problems related to breast cancer in the past 12 months?

☐None ☐1 ☐2 ☐3 or more

7. When was the date of your last discussion of symptoms? Date_____

☐Within the past 3 months
☐Between 4 - 6 months ago
☐Between 7– 12 months ago
☐More than 12 months ago
☐Not sure

8. Do you have an appointment to discuss any symptoms or problems?

- [ ] I have an appointment When? _____
- [ ] I have tried to make an appointment recently but I do not have one
- [ ] I have no appointment

Section 4A

The interviewer will let you know if you need to answer the questions on this page.

9a. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 6 months from the last time I did so."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

10a. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11a. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

12a. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 4B

The interviewer will let you know if you need to answer the questions on this page.

9b. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 6 months who will ask me about any symptoms or problems related to breast cancer."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

10b. How much control do you have over going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11b. Going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

12b. Most people who are important to you think you should go to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 4C

The interviewer will let you know if you need to answer the questions on this page.

9c. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 12 months from the last time I did so."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

10c. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11c. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so will be ….

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

12c. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 4D

The interviewer will let you know if you need to answer the questions on this page.

9d. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 12 months who will ask me about any symptoms or problems related to breast cancer."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

10d. How much control do you have over going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

11d. Going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer will be ….

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

12d. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 5

1. Do you know how to do a breast self-exam (check your own breasts)?

☐Yes ☐No ☐Not sure

2. How confident are you that you are able to do a breast self-exam correctly?

☐Very confident
☐Fairly confident
☐A little confident
☐Not at all confident

3. Since you completed your treatment for breast cancer, has your doctor ever recommended that you do a breast self-exam?

☐Yes ☐No ☐Not sure

4. Since you completed breast cancer treatment, have you done a breast self-exam?

☐Yes ☐No ☐Not sure

5. How many breast self exams have you done in the past 12 months?

☐None ☐1-4 ☐5-9 ☐10-12 ☐ 13 or more

6. When was your last breast self-exam? Date _____

☐Within the past week
☐Within the past month
☐Within the past 2-3 months
☐Within the past 4-6 months
☐Within the 7-12 months
☐More than 12 months ago
☐Not sure

7. How often do you perform breast self-examination (BSE)?
☐Never
☐At least once a day
☐Once a week
☐Twice a month
☐Once a month
☐Once every other month (six times a year)
☐Two or three times a year
☐Once a year
☐When I have symptoms or problems

8. How much do you agree or disagree with this statement: "I intend to do breast self exam every month?"

☐ Strongly disagree
☐ Disagree
☐ Not sure/undecided
☐ Agree
☐ Strongly agree

9. How much control do you have doing breast self-exam every month?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

10. Doing breast self-exam every month would be....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

11. Most people who are important to you think you should do a breast self-exam every month.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 6

1. Since you completed breast cancer treatment, has your doctor ever recommended that you have a pelvic exam and pap test?

☐Yes ☐No ☐Not sure

2. Since you completed breast cancer treatment, have you had a pelvic exam and pap test?

☐Yes ☐No ☐Not sure

3. Since you completed breast cancer treatment, how many pelvic exams/pap tests have you had in total?

☐None ☐1 ☐2 ☐3 ☐4 ☐5 or more

4. Were any of these pelvic exams/pap tests <u>not</u> routine (you had it because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

5. How many pelvic exams/pap tests have you had in the past 12 months?

☐None ☐1 ☐2 ☐3 or more

6. When was your last pelvic exam/pap test? Date_____

☐Within the past 6 months
☐Within the past 7-12 months
☐Within the past 13-24 months years
☐More than 24 months ago
☐Not sure

7. Do you have an appointment to have a pelvic exam and pap test?

☐I have an appointment When? _____
☐I have tried to make an appointment recently but I do not have one
☐I have no appointment

Section 6A

The interviewer will let you know if you need to answer the questions on this page.

8a. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test at least 12 months from the date of my last pelvic exam/pap test."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

9a. How much control do you have over having a pelvic exam and pap test at least 12 months from the date of your last one?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

10a. Having a pelvic exam and pap test at least 12 months from the date of your last one will be….

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

11c. Most people who are important to you think you should have a pelvic exam and pap test at least 12 months from the date of your last one.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 6B

The interviewer will let you know if you need to answer the questions on this page.

8b. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test sometime in the next 12 months."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

9b. How much control do you have over having a pelvic exam and pap test sometime in the next 12 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

10b. Getting your next pelvic exam and pap test sometime in the next 12 months will be….

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

11b. Most people who are important to you think you should have a pelvic exam and pap test sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 7

1. Since completing breast cancer treatment, have you had other types of follow-up tests? **Select all that apply.**

☐ CT scan or CAT scan (Computed tomography scan: A computerized x-ray procedure that produces cross-sectional images of the body).

☐ Ultrasound (also known as a sonogram, this technique uses sound waves to make pictures of the body organs and obtain images for medical diagnosis).

☐ MRI (Magnetic resonance imaging: A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body).

☐ X-rays (electromagnetic radiation used to produce images of bones, organs, and internal tissues)

☐ Blood tests

☐ Bone scans (A technique to create images of bones on a computer screen or on film after an injection of a small amount of radioactive material)

☐ Other _____

_____

3. Since completing breast cancer treatment

a. Have you made any changes to your diet?	☐Yes	☐No
b. Have you decreased the amount of fat in your diet?	☐Yes	☐No
c. Have you increased the amount of fiber in your diet?	☐Yes	☐No
d. Have you decreased the amount of red meat in your diet?	☐Yes	☐No
e. Have you increased your use of vitamins and dietary supplements?	☐Yes	☐No
f. Have you increased your use of herbal remedies?	☐Yes	☐No
g. Have you started exercising more?	☐Yes	☐No

Section 8

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below:

1=Strongly disagree
2=Moderately disagree
3=Undecided/ Not sure
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

The first set of questions asks about the follow-up care you may be receiving since you have completed breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
1.	I would probably not have follow-up care unless I had some breast symptoms or discomfort.	1	2	3	4	5
2.	Those people who are close to me will benefit if I have regular breast cancer follow-up care.	1	2	3	4	5
3.	If follow-up care finds a problem, whatever is there will probably be too far along to do anything about it anyway.	1	2	3	4	5
4.	I would be more likely to have regular follow-up care if my doctor told me how important it is.	1	2	3	4	5
5.	Regular follow-up care is too expensive for me.	1	2	3	4	5
6.	I don't have time for regular follow-up care.	1	2	3	4	5
7.	Regular follow-up care gives me a feeling of control over my health.	1	2	3	4	5
8.	If I eat a healthy diet, I will lower my risk of getting breast cancer far enough that I probably do not need regular follow-up care.	1	2	3	4	5
9.	Regular follow-up care gives me peace of mind over my health.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
10.	I would probably not have regular follow-up care if my doctor seemed to doubt I really needed it.	1	2	3	4	5
11.	Regular follow-up care causes me unnecessary worry.	1	2	3	4	5
12.	I am afraid to have regular follow-up care because I might find out something is wrong.	1	2	3	4	5

The next set of questions refer to feelings about follow-up care after breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
13.	I would be ashamed if follow-up care found that I have breast cancer again.	1	2	3	4	5
14.	Other people would view me negatively if follow-up care found that I had breast cancer again.	1	2	3	4	5
15.	I would be angry if follow-up care found that I had breast cancer again.	1	2	3	4	5
16.	I would be frightened if follow-up care found that I had breast cancer again.	1	2	3	4	5
17.	I would not be able to handle it emotionally if follow-up care found that I had breast cancer again.	1	2	3	4	5
18.	I would feel a sense of hopelessness and despair if follow-up care found that I had breast cancer again.	1	2	3	4	5

The next set of questions refer to mammograms and breast self-exams.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
19.	Having a mammogram is painful.	1	2	3	4	5
20.	Having a mammogram is embarrassing.	1	2	3	4	5
21.	If I receive a clinical breast exam from a doctor or nurse, I don't need to have a mammogram.	1	2	3	4	5
22.	If I do breast self-exam (check my own breasts), I don't need to have a mammogram.	1	2	3	4	5
23.	The results of mammograms are not trustworthy.	1	2	3	4	5
24.	Having a mammogram exposes me to unnecessary radiation.	1	2	3	4	5
25.	I am uncomfortable doing breast self-exam (checking my own breasts) because since I was treated for cancer, I'm not sure if what I'm feeling during the exam is normal or not.	1	2	3	4	5
26.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to look at my breasts since being treated for cancer.	1	2	3	4	5
27.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to touch my breasts since being treated for cancer.	1	2	3	4	5

Section 9

Think about how much you agree or disagree with each of the following statements about follow-up care after breast cancer treatment. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree
2=Moderately disagree
3=Undecided
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly Disagree	Moderately Disagree	Undecided / Not sure	Moderately Agree	Strongly Agree
1.	I have talked to or heard from breast cancer survivors who have regular follow-up care.	1	2	3	4	5
2.	I have talked to or heard from breast cancer survivors who benefit from regular follow-up care.	1	2	3	4	5
3.	I have received information about regular follow-up care that is useful to me as a Black survivor.	1	2	3	4	5
4.	I have received trustworthy information about regular follow-up care.	1	2	3	4	5
5.	I have talked to or heard from friends think I should have regular follow-up care.	1	2	3	4	5
6.	I have talked to or heard from my spouse or partner who thinks I should have regular follow-up care. ***Not applicable***	1	2	3	4	5
7.	I have talked to or heard from family members who think I should have regular follow-up care.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided/ Not sure	Moderately agree	Strongly agree
8.	I have talked to or heard from people in my church or house of worship who think I should have regular follow-up care. ***Not applicable***	1	2	3	4	5
9.	I have talked to or heard from my doctors or other healthcare providers who think I should have regular follow-up care.	1	2	3	4	5
10.	I have talked to or heard from other breast cancer survivors think I should have regular follow-up care.					
11.	I have talked to or heard from other Black women think I should have regular follow-up care.	1	2	3	4	5
12.	Most people who are important to me think I should have regular follow-up care.	1	2	3	4	5

Section 10

Please answer the following questions True, False, or Not sure.

1.	Black breast cancer survivors are more likely to have a breast cancer recurrence compared to White survivors.	☐True	☐False	☐Not sure
2.	Younger breast cancer survivors are more likely to have a breast cancer recurrence compared to older survivors.	☐True	☐False	☐Not sure
3.	Breast cancer recurrence is more treatable and better controlled if it is found at an early stage.	☐True	☐False	☐Not sure
4.	Most breast cancer recurrences are found within the first 5 years following diagnosis and treatment.	☐True	☐False	☐Not sure
5.	Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.	☐True	☐False	☐Not sure
6.	Breast cancer survivors only need to have physical exams about once a year after they have completed breast cancer treatment.	☐True	☐False	☐Not sure
7.	Breast cancer survivors should have regular pelvic exams and pap tests (at least once a year).	☐True	☐False	☐Not sure
8.	Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.	☐True	☐False	☐Not sure
9.	Women diagnosed with breast cancer need to examine their own breasts every day.	☐True	☐False	☐Not sure
10.	Chest pain and problems with breathing can be signs of breast cancer recurrence.	☐True	☐False	☐Not sure

Section II

1. On a scale of 0 to 100 where 0 means "no chance" and 100 means "guaranteed to happen," how would your rate your chances of getting breast cancer again? _____

2. What do you think your chances are of being diagnosed with breast cancer again?
   - ☐ Very low
   - ☐ Low
   - ☐ Average
   - ☐ High
   - ☐ Very high
   - ☐ Not sure

3. On a scale of 0 to 100 where 0 means "not bad at all" and 100 means "the worst possible situation", how bad would it be if you were to get breast cancer again? _____

4. On a scale of 0% to 100%, what percentage of all breast cancer survivors do you think will get breast cancer again? _____

5. Compared to other women who have had breast cancer, what do you think your chances are of being diagnosed with breast cancer again?
   - ☐ I am at much less risk than others
   - ☐ I am at somewhat less risk than others
   - ☐ My risk is about the same as others
   - ☐ I am at somewhat higher risk than others
   - ☐ I am at much higher risk than others
   - ☐ Not sure

6. How worried are you about getting breast cancer again?
   - ☐ Extremely worried
   - ☐ Moderately worried
   - ☐ Undecided/not sure
   - ☐ A little worried
   - ☐ Not at all worried

7. What do you think your chances are of getting a new cancer of some other type?
   - ☐ I am at much less risk than others
   - ☐ I am at somewhat less risk than others
   - ☐ My risk is about the same as others
   - ☐ I am at somewhat higher risk than others
   - ☐ I am at much higher risk than others
   - ☐ Not sure

8. How worried are you about getting a new cancer of some other type?
   - ☐ Extremely worried
   - ☐ Moderately worried
   - ☐ Undecided/not sure
   - ☐ A little worried
   - ☐ Not at all worried

9. What do you think your chances are of developing heart disease (high blood pressure, stroke, heart attack, etc.)?

- ☐ I am at much less risk than others
- ☐ I am at somewhat less risk than others
- ☐ My risk is about the same as others
- ☐ I am at somewhat higher risk than others
- ☐ I am at much higher risk than others
- ☐ Not sure
- ☐ I have already been diagnosed with heart disease

10. How worried are you about developing heart disease?

- ☐ Extremely worried
- ☐ Moderately worried
- ☐ Undecided/not sure
- ☐ A little worried
- ☐ Not at all worried
- ☐ I have already been diagnosed with heart disease

Section 12

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below:

1=Strongly disagree
2= Disagree
3=Agree
4=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly disagree	Disagree	Agree	Strongly agree
1.	Overall, being Black has very little to do with how I feel about myself.	1	2	3	4
2.	In general, being Black is an important part of my self-image.	1	2	3	4
3.	My destiny is tied to the destiny of other Black people.	1	2	3	4
4.	Being Black is unimportant to my sense of what kind of person I am	1	2	3	4
5.	I have a strong sense of belonging to Black people.	1	2	3	4
6.	I have a strong attachment to other Black people.	1	2	3	4
7.	Being Black is an important reflection of who I am.	1	2	3	4
8.	Being Black is not a major factor in my social relationships.	1	2	3	4

Section 13

Below is a list of comments made by people about stressful events. Please check each item, indicating how frequently these comments were true for you during the past week including today about breast cancer. Circle the appropriate number. If they did not occur during that time, please mark the "not at all" column.

		Not at all	Rarely	Sometimes	Often
1.	Thought about breast cancer when I didn't mean to.	0	1	3	5
2.	I avoided letting myself get upset when I thought about it or was reminded of breast cancer.	0	1	3	5
3.	I tried to remove breast cancer from memory.	0	1	3	5
4.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about breast cancer that came into my mind.	0	1	3	5
5.	I had waves of strong feelings about breast cancer.	0	1	3	5
6.	I stayed away from reminders about breast cancer.	0	1	3	5
7.	I had dreams about breast cancer.	0	1	3	5
8.	I felt as if breast cancer was unreal.	0	1	3	5
9.	I tried not to talk about breast cancer.	0	1	3	5
10.	Pictures about breast cancer popped into my mind.	0	1	3	5
11.	Other things kept making me think about breast cancer .	0	1	3	5
12.	I was aware that I had a lot of feelings about breast cancer but I didn't deal with them.	0	1	3	5
13.	I tried not to think about breast cancer .	0	1	3	5
14.	Any reminder brought back feelings about breast cancer.	0	1	3	5
15.	My feelings about breast cancer were kind of numb.	0	1	3	5

Section 14

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below:

1=Strongly disagree
2= Disagree
3=Agree
4=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly disagree	Disagree	Agree	Strongly agree
1.	I am able to get medical care whenever I need it.	1	2	3	4
2.	Sometimes it is a problem to cover my share of the cost for a medical visit.	1	2	3	4
3.	Sometimes I go without the medical care I need because it is too expensive.	1	2	3	4
4.	Places where I can get medical care are conveniently located.	1	2	3	4
5.	If I have a medical question, I can reach a doctor or nurse for help.	1	2	3	4
6.	Health care providers often don't listen to people.	1	2	3	4
7.	I have easy access to the medical specialists I need.	1	2	3	4
8.	I don't worry much about the cost when I know I need to seek medical care.	1	2	3	4
9.	I see a different health care provider almost every time I go to an appointment.	1	2	3	4
10.	Money is an issue to me when I need to see the doctor.	1	2	3	4

Section 15

1. How much have you heard or read about genetic testing for breast cancer risk?

   ☐ Almost Nothing
   ☐ Relatively Little
   ☐ A Fair Amount
   ☐ A lot

2. At the present time, how interested are you in getting genetic testing for breast cancer risk?
   ☐ Not at all interested
   ☐ Slightly interested
   ☐ Moderately interested
   ☐ Very interested

3. Now that such a test is currently available, which of the following best describes your intentions?
   ☐ I have already donated a blood sample for genetic testing.
   ☐ I plan to take the test as soon as possible (within the next 30 days).
   ☐ I plan to take the test sometime in the near future (within the next 6 months).
   ☐ I do not plan to take the test in the near future (not within the next 6 months).
   ☐ I do not plan to take the test at all.

Is there anything else you would like to share with me related to breast cancer recurrence that I have not asked you about?

_____
_____
_____
_____
_____
_____

May we have your permission to contact you in the future about other research studies?

☐ Yes ☐ No

Questionnaire 1 – Part 2

Name _____ Date _____

This is Part 2 of the questionnaire. Please complete this on your own and mail this back to us in the WHITE envelope.

Remember:

- Provide your name and date at the top
- All the information you provide is confidential and private.
- You may skip any question you do not feel comfortable answering.

Last updated 4/7/05, 1:24 PM (HT)

Section 1

1. Are you a member of a church or other place of worship?

   ☐ Yes
   ☐ No

2. How often do you attend church or other religious services?
   ☐ More than once per week
   ☐ Once a week
   ☐ A few times a month
   ☐ A few times a year
   ☐ Once a year or less
   ☐ Never

3. How often do you spend time in private religious activities, such as prayer, meditation or Bible study?
   ☐ More than once per week
   ☐ Once a week
   ☐ A few times a month
   ☐ A few times a year
   ☐ Once a year or less
   ☐ Never

Please consider the following statements. Think about how true each one is for you and then indicate how strongly you agree or disagree with each one.

1. I talk openly about my faith with others.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
2. I often read religious books, magazines, or pamphlets.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
3. I often watch or listen to religious programs on television or radio	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
4. My spiritual beliefs are the foundation of my whole approach to life	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
5. I am often aware of the presence of God in my life.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
6. I have a personal relationship with God.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
7. When I am ill, I pray for healing.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**

8. I pray often.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
9. I rely on God to keep me in good health.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
10. If I lead a good spiritual life, I will stay healthy.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
11. If I stay healthy, it is because I am right with God	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**
12. Through my faith in God, I can stay healthy.	☐ **Strongly disagree**	☐ **Disagree**	☐ **Agree**	☐ **Strongly agree**

Section 2

These questions ask about your beliefs about the care you and other people of your racial and ethnic group receive from doctors, nurses, and other staff people in the health care system. Please indicate how much you agree or disagree with the following statements.

Check one answer for each question.

1.	Doctors and health care workers sometimes hide information from patients who belong to my ethnic group.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
2.	Doctors have the best interests of people of my ethnic group in mind.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
3.	People of my ethnic group should not confide in doctors and health care workers because it will be used against them.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
4.	People of my ethnic group should be suspicious of information from doctors and health care workers.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
5.	People of my ethnic group cannot trust doctors and health care workers.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
6.	People of my ethnic group should be suspicious of modern medicine.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
7.	Doctors and health care workers treat people of my ethnic group like "guinea pigs".	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
8.	People of my ethnic group receive the same medical care from doctors and health care workers as people from other groups.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
9.	Doctors and health care workers do not take the medical complaints of people of my ethnic group seriously.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
10.	People of my ethnic group are treated the same as people of other groups by doctors and health care workers.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree

11.	In most hospitals, people of different ethnic groups receive the same kind of care.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree
12.	I have personally been treated poorly or unfairly by doctors or health care workers because of my ethnicity.	☐ Strongly Agree	☐ Agree	☐ Not Sure	☐ Disagree	☐ Strongly Disagree

Please check the one box on each line that best matches your answer. Please think about the doctor you see most often for your follow-up care since you have been completed breast cancer treatment.

Which doctor do you see most often for your follow-up care since you have been completed breast cancer treatment?

- ☐ Surgeon
- ☐ Radiation oncologist
- ☐ Medical oncologist
- ☐ Primary care physician
- ☐ Gynecologist
- ☐ Other _____

1.	I doubt that my doctor really cares about me as a person.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
2.	My doctor is usually considerate of my needs and puts them first.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
3.	I trust my doctor so much I always try to follow his/her advice.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
4.	If my doctor tells me something is so, then it must be true.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
5.	I sometimes distrust my doctor□s opinion and would like a second one.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
6.	I trust my doctor□s judgments about my medical care.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
7.	I feel my doctor does not do everything he/she should for my medical care.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
8.	I trust my doctor to put my medical needs above all other considerations when treating my medical problems.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**

9.	My doctor is a real expert in taking care of medical problems like mine.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
10.	I trust my doctor to tell me if a mistake was made about my treatment.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**
11.	I sometimes worry that my doctor may not keep the information we discuss totally private.	☐ **Strongly Agree**	☐ **Agree**	☐ **Not Sure**	☐ **Disagree**	☐ **Strongly Disagree**

Section 3

1. Which doctor do you see most often for your follow-up care since you have been completed breast cancer treatment?

- ☐ Surgeon
- ☐ Radiation oncologist
- ☐ Medical oncologist
- ☐ Primary care physician
- ☐ Gynecologist
- ☐ **Other** _____

2. Please check the box next to the statement that best matches the involvement you prefer to have in making decisions about the follow-up care you receive since you have finished breast cancer treatment.

Please think about the doctor you see most often for your follow-up care since you have been completed breast cancer treatment.

Only select one statement.

- □ I prefer to make the decisions about what care I will receive.
- □ I prefer to make the final decisions about my care after seriously considering my doctor's opinion.
- □ I prefer that my doctor and I share responsibility for deciding what care is best for me.
- □ I prefer that my doctor make the final decisions about what care will be used but seriously consider my opinion.
- ¬ I prefer to leave all decisions regarding care to my doctor.

3. Please check the box next to the statement that best matches the involvement you actually have in decisions about the follow-up care you have receive since finishing your breast cancer treatment.

Only select one statement.

- □ I make the decisions about the care I receive.
- □ I make the final decisions about my care after seriously considering my doctor's opinion.
- □ My doctor and I share responsibility for deciding what care is best for me.
- □ My doctor makes the final decisions about what care I receive but the doctor seriously considers my opinion.
- □ I leave the decisions regarding care to my doctor.

Section 4

The following questions ask you to tell us about any worries you may have about the possibility of breast cancer recurrence. By recurrence we mean the breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast.

Although most women who have been diagnosed with early stage breast cancer will never have another problem with the cancer, we are aware that many women do worry about this possibility. Other women may not worry about recurrence at all. Either way, your answers to these questions are very important to us. We understand that it may be upsetting to think about or answer questions about the possibility of recurrence. However we need you help to understand how women think about this possibility.

For the following four questions please circle the number that comes closet to the way you feel. For example, for the first question you should circle "1" if you don't think about recurrence at all, circle "6" if you think about recurrence all the time, or circle "2", "3", "4" or "5" if the amount of time you spend thinking about recurrence is somewhere in between.

1. How much time do you spend thinking about the possibility that your breast cancer could recur?

1	2	3	4	5	6
I Don't Think About It At All					**I Think About It All The Time**

2. How much does the possibility that your breast cancer could recur upset you?

1	2	3	4	5	6
It Does Not at all					**It Makes Me Extremely Upset**

3. How often do you worry about the possibility that your breast cancer could recur?

1	2	3	4	5	6
I Never Worry About It					**I Worry About It All The Time**

4. How afraid are you that your breast cancer may recur?

1	2	3	4	5	6
Not At All Afraid					**Very Afraid**

Now we are interested in what your concerns are regarding a possible recurrence of breast cancer. When thinking about the possibility of recurrence what is it about that possibility that you worry about?

Although each of the following items may be possible consequence of recurrence, we are really interested in whether you actually worry about any of these things occurring. For example, you may believe that a recurrence of breast cancer could require further surgery. We would like to know whether you ever actually worry about this possibility.

For the following questions, please circle the number indicating how much you worry about each of the following items. If you do not worry about an item or if you think it does not apply to you, please check "Not at all."

I worry that a recurrence of breast cancer would:

5.	Upset me emotionally	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
6.	Keep me from doing the things I had planned to do	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
7.	Threaten my physical health	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
8.	Make me feel I am less of a woman	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
9.	Require chemotherapy	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
10.	Hurt my relationships with friends and family	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
11.	Make me feel that I don't have control over my life	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
12.	Threaten my identity (how I see myself)	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
13.	Interfere with my physical ability to carry out daily activities	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**
14.	Threaten life	☐ **Not at all**	☐ **A Little**	☐ **Moderately**	☐ **A lot**	☐ **Extremely**

15.	Harm my self–confidence	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
16.	Be more serious than the first diagnosis	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
17.	Cause financial problems for me	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
18.	Interfere with my sense of sexuality	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
19.	Require radiation treatment	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
20.	Cause financial problems for me	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
21.	Mean losing my breast(s)	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
22.	Interfere with my ability to plan for the future	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
23.	Threaten my spirituality or faith	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
24.	Keep me from fulfilling important roles (in my job or at home)	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
25.	Lead me to feel less feminine	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
26.	Require further surgery	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
27.	Cause me to die	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
28.	Damage my romantic relationship(s)	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
29.	Keep me from fulfilling my responsibilities (in my job or at home)	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely
30.	Make me feel badly about how my body looks or feels	☐ Not at all	☐ A Little	☐ Moderately	☐ A lot	☐ Extremely

Questionnaire 2

(One-month follow-up assessment)

Thank you for participating in our study *Survivors in Spirit*!

Please remember:

- **Do not complete this interview until your scheduled telephone interview.**
- **The questionnaire is for you to read while you are being interviewed.**
- **All information you give is confidential and private.**

Last updated 4/8/05, 1:33 PM (HT)

Section 1

1. Since the last interview, has your doctor recommended that you have mammogram?

☐Yes ☐No ☐Not sure

2. Since the last interview, have you had a mammogram?

☐Yes ☐No ☐Not sure

If yes, when? _____

3. If yes, was this mammogram <u>not</u> routine (you had it because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

4. Do you have an appointment to have a mammogram?

☐I have an appointment When? _____
☐I have tried to make an appointment since the last interview but I do not have one
☐I have no appointment

Section 1A

5a. How much do you agree or disagree with this statement: "I intend to have a mammogram at least 12 months from the date of my last mammogram."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

6a. How much control do you have over getting a mammogram at least 12 months from the date of your last mammogram?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

7a. Having a mammogram at least 12 months from the date of your last mammogram will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

8a. Please tell me how much you agree or disagree with the following statements. Do you think that having a mammogram at least 12 months from the date of your last mammogram would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

9a. Most people who are important to you think you should have a mammogram at least 12 months from your last one.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 1B

5b. How much do you agree or disagree with this statement: "I intend to have a mammogram sometime in the next 12 months."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

6b. How much control do you have over getting a mammogram sometime in the next 12 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

7b. Having a mammogram sometime in the next 12 months will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

8b. Please tell me how much you agree or disagree with the following statements. Do you think that getting a mammogram in the next 12 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

9b. Most people who are important to you think you should have a mammogram sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2

1. Since the last interview, has your doctor recommended that you have a physical examination (physical examination is an evaluation of the body and its functions using inspection, feeling with the hands, tapping with the fingers, and listening)?

☐Yes ☐No ☐Not sure

2. Since the last interview, have you had a physical examination?

☐Yes ☐No ☐Not sure

If yes, when? _____

3. If yes, what type of doctor did you see? **You may indicate more than one type of doctor.**

☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

4. Was this exam not routine (you went because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

5. Do you have an appointment to have a physical examination?

☐I have an appointment When? _____
☐I have tried to make an appointment recently but I do not have one
☐I have no appointment

Section 2A

6a. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 6 months from the date of my last exam."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

7a. How much control do you have over having a physical examination at least 6 months from the date of your last exam?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8a. Having a physical examination at least 6 months from the date of your last exam will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9a. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 6 months from the date of your last exam would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10a. Most people who are important to you think you should have a physical examination at least 6 months from the date of your last exam.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2B

5b. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 6 months."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

7b. How much control do you have over having a physical examination sometime in the next 6 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8b. Having a physical examination sometime in the next 6 months will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9b. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination sometime in the next 6 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10b. Most people who are important to you think you should have a physical examination in the next 6 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2C

6c. How much do you agree or disagree with this statement: "I intend to have a physical examination at least 12 months from the date of my last exam."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

7c. How much control do you have over having a physical examination at least 12 months from the date of your last one?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8c. Having a physical examination at least 12 months from the date of your last one will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ *Very difficult*

9c. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination at least 12 months from the date of your last one would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10c. Most people who are important to you think you should have a physical examination at least 12 months from the date of your last one.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 2D

6d. How much do you agree or disagree with this statement: "I intend to have a physical examination sometime in the next 12 months."

☐ Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

7d. How much control do you have over having a physical examination sometime in the next 12 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8d. Having a physical examination sometime in the next 12 months will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9d. Please tell me how much you agree or disagree with the following statements. Do you think that having a physical examination sometime in the next 12 months would be....

		Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

10d. Most people who are important to you think you should have a physical examination sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3

1. Since the last interview, has your doctor recommended that see a doctor who can ask you about symptoms or problems related to breast cancer?

☐Yes ☐No ☐Not sure

2. Since the last interview, has a doctor asked you about any symptoms or problems related to breast cancer?

☐Yes ☐No ☐Not sure

If yes, when? _____

3. If yes, what type of doctor asked you about symptoms or problems related to breast cancer? **You may indicate more than one type of doctor.**

☐ Surgeon
☐ Radiation oncologist
☐ Medical oncologist
☐ Primary care physician
☐ Gynecologist
☐ Other _____

4. Was this discussion not routine (you went because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

5. Do you have an appointment to discuss any symptoms or problems related to breast cancer?

☐I have an appointment When? _____
☐I have tried to make an appointment recently but I do not have one
☐I have no appointment

Section 3A

6a. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 6 months from the last time I did so."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

7a. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8a. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so will be ….

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9a. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 6 months from the last time you did so.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3B

6b. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 6 months who will ask me about any symptoms or problems related to breast cancer."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

7b. How much control do you have over going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8b. Going to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9b. Most people who are important to you think you should go to see a doctor sometime in the next 6 months who will ask you about any symptoms or problems related to breast cancer.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3C

6c. How much do you agree or disagree with this statement: "I intend to see a doctor who will ask me about any symptoms or problems related to breast cancer at least 12 months from the last time I did so."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

7c. How much control do you have over going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8c. Going to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so will be ….

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9c. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer at least 12 months from the last time you did so.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 3D

6d. How much do you agree or disagree with this statement: "I intend to see a doctor sometime in the next 12 months who will ask me about any symptoms or problems related to breast cancer."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

7d. How much control do you have over going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

8d. Going to see a doctor sometime in the next 12 months who will ask you about any symptoms or problems related to breast cancer will be ....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

9d. Most people who are important to you think you should go to see a doctor who will ask you about any symptoms or problems related to breast cancer sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 4

1. Do you know how to do a breast self-exam?

☐Yes ☐No ☐Not sure

2. How confident are you that you are able to do a breast self-exam correctly?

☐Very confident
☐Fairly confident
☐A little confident
☐Not at all confident

3. Since the last interview, has your doctor recommended that you do a breast self-exam (check your own breasts)?

☐Yes ☐No ☐Not sure

4. Since the last interview, have you done a breast self-exam?

☐Yes ☐No ☐Not sure

. When was your last breast self-exam? Date _____

☐Within the past week
☐Within the past month
☐Within the past 3 months
☐Within the past 6 months
☐Within the past year
☐More than 1 year ago
☐Not sure

6. How often do you perform breast self-examination (BSE)?
☐Never
☐At least once a day
☐Once a week
☐Twice a month
☐Once a month
☐Once every other month (six times a year)
☐Two are three times a year
☐Once a year
☐When I have symptoms or problems

7. How much do you agree or disagree with this statement: "I intend to do breast self exam every month?"
☐Strongly disagree
☐Disagree
☐Not sure/undecided
☐Agree
☐Strongly agree

8. How much control do you have doing breast self-exam every month?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

9. Doing breast self-exam every month would be....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

10. Most people who are important to you think you should do a breast self-exam every month.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 5

1. Since the last interview, has your doctor recommended that you have a pelvic exam and pap test?

☐Yes ☐No ☐Not sure

2. Since the last interview, have you had a pelvic exam or pap test?

☐Yes ☐No ☐Not sure

If yes, when? _____

3. Was this pelvic exam/pap test not routine (you had it because you had symptoms or problems)?

☐Yes ☐No ☐Not sure

4. Do you have an appointment to have a pelvic exam and pap test?

☐I have an appointment When? _____
☐I have tried to make an appointment recently but I do not have one
☐I have no appointment

Section 5A

5a. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test at least 12 months from the date of my last pelvic exam/pap test."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

6a. How much control do you have over having a pelvic exam and pap test at least 12 months from the date of your last one?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

7a. Having a pelvic exam and pap test at least 12 months from the date of your last one will be....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

8a. Most people who are important to you think you should have a pelvic exam and pap test at least 12 months from the date of your last one.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 5B

5b. How much do you agree or disagree with this statement: "I intend to have a pelvic exam/pap test sometime in the next 12 months."

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

6b. How much control do you have over having a pelvic exam and pap test sometime in the next 12 months?

☐ Complete control
☐ A lot of control
☐ A fair amount of control
☐ Very little control
☐ No control

7b. Getting your next pelvic exam and pap test sometime in the next 12 months will be....

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult

8b. Most people who are important to you think you should have a pelvic exam and pap test sometime in the next 12 months.

☐ Strongly Disagree
☐ Disagree
☐ Not Sure
☐ Agree
☐ Strongly Agree

Section 6

1. Since the last interview, have you had other types of follow-up tests? **Select all that apply.**

☐ CT scan or CAT scan (Computed tomography scan: A computerized x-ray procedure that produces cross-sectional images of the body.

☐ Ultrasound (also known as a sonogram, this technique uses sound waves to make pictures of the body organs and obtain images for medical diagnosis

☐ MRI (Magnetic resonance imaging: A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.

☐ X-rays (electromagnetic radiation used to produce images of bones, organs, and internal tissues)

☐ Blood tests

☐ Bone scans (A technique to create images of bones on a computer screen or on film after an injection of a small amount of radioactive material)

☐ Other _____

Section 7

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree
2=Moderately disagree
3=Undecided
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

The first set of questions asks about the follow-up care you may be receiving since you have completed breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
1.	I would probably not have follow-up care unless I had some breast symptoms or discomfort.	1	2	3	4	5
2.	Those people who are close to me will benefit if I have regular breast cancer follow-up care.	1	2	3	4	5
3.	If follow-up care finds a problem, whatever is there will probably be too far along to do anything about it anyway.	1	2	3	4	5
4.	I would be more likely to have regular follow-up care if my doctor told me how important it is.	1	2	3	4	5
5.	Regular follow-up care is too expensive for me.	1	2	3	4	5
6.	I don't have time for regular follow-up care.	1	2	3	4	5
7.	Regular follow-up care gives me a feeling of control over my health.	1	2	3	4	5
8.	If I eat a healthy diet, I will lower my risk of getting breast cancer far enough that I probably do not need regular follow-up care.	1	2	3	4	5
9.	Regular follow-up care gives me peace of mind over my health.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
10.	I would probably not have regular follow-up care if my doctor seemed to doubt I really needed it.	1	2	3	4	5
11.	Regular follow-up care causes me unnecessary worry.	1	2	3	4	5
12.	I am afraid to have regular follow-up care because I might find out something is wrong.	1	2	3	4	5

The next set of questions refer to feelings about follow-up care after breast cancer treatment.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
13.	I would be ashamed if follow-up care found that I have breast cancer again.	1	2	3	4	5
14.	Other people would view me negatively if follow-up care found that I had breast cancer again.	1	2	3	4	5
15.	I would be angry if follow-up care found that I had breast cancer again.	1	2	3	4	5
16.	I would be frightened if follow-up care found that I had breast cancer again.	1	2	3	4	5
17.	I would not be able to handle it emotionally if follow-up care found that I had breast cancer again.	1	2	3	4	5
18.	I would feel a sense of hopelessness and despair if follow-up care found that I had breast cancer again.	1	2	3	4	5

The next set of questions refer to mammograms and breast self-exams.

		Strongly disagree	Moderately disagree	Undecided /Not sure	Moderately agree	Strongly agree
19.	Having a mammogram is painful.	1	2	3	4	5
20.	Having a mammogram is embarrassing.	1	2	3	4	5
21.	If I receive a clinical breast exam from a doctor or nurse, I don't need to have a mammogram.	1	2	3	4	5
22.	If I do breast self-exam (check my own breasts), I don't need to have a mammogram.	1	2	3	4	5
23.	The results of mammograms are not trustworthy.	1	2	3	4	5
24.	Having a mammogram exposes me to unnecessary radiation.	1	2	3	4	5
25.	I am uncomfortable doing breast self-exam (checking my own breasts) because since I was treated for cancer, I'm not sure if what I'm feeling during the exam is normal or not.	1	2	3	4	5
26.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to look at my breasts since being treated for cancer.	1	2	3	4	5
27.	I am uncomfortable doing breast self-exam (checking my own breasts) because it is hard for me to touch my breasts since being treated for cancer.	1	2	3	4	5

Section 8

Think about how much you agree or disagree with each of the following statements about follow-up care after breast cancer treatment. Please indicate how much you agree or disagree with the following statements using the key below

1=Strongly disagree
2=Moderately disagree
3=Undecided
4=Moderately agree
5=Strongly agree

Choose the number that best matches your agreement with each statement.

		Strongly Disagree	Moderately Disagree	Undecided / Not sure	Moderately Agree	Strongly Agree
1.	I have talked to or heard from breast cancer survivors who have regular follow-up care.	1	2	3	4	5
2.	I have talked to or heard from breast cancer survivors who benefit from regular follow-up care.	1	2	3	4	5
3.	I have received information about regular follow-up care that is useful to me as a Black survivor.	1	2	3	4	5
4.	I have received trustworthy information about regular follow-up care.	1	2	3	4	5
5.	I have talked to or heard from friends think I should have regular follow-up care.	1	2	3	4	5
6.	I have talked to or heard from my spouse or partner who thinks I should have regular follow-up care. ***Not applicable***	1	2	3	4	5
7.	I have talked to or heard from family members who think I should have regular follow-up care.	1	2	3	4	5

		Strongly disagree	Moderately disagree	Undecided/ Not sure	Moderately agree	Strongly agree
8.	I have talked to or heard from people in my church or house of worship who think I should have regular follow-up care. ***Not applicable***	1	2	3	4	5
9.	I have talked to or heard from my doctors or other healthcare providers who think I should have regular follow-up care.	1	2	3	4	5
10.	I have talked to or heard from other breast cancer survivors think I should have regular follow-up care.					
11.	I have talked to or heard from other Black women think I should have regular follow-up care.	1	2	3	4	5
12.	Most people who are important to me think I should have regular follow-up care.	1	2	3	4	5

Section 9
Breast Cancer Surveillance Knowledge Questionnaire

Please answer the following questions True, False, or Not sure.

1.	Black breast cancer survivors are more likely to have a breast cancer recurrence compared to White survivors.	☐True	☐False	☐Not sure
2.	Younger breast cancer survivors are more likely to have a breast cancer recurrence compared to older survivors.	☐True	☐False	☐Not sure
3.	Breast cancer recurrence is more treatable and better controlled if it is found at an early stage.	☐True	☐False	☐Not sure
4.	Most breast cancer recurrences are found within the first 5 years following diagnosis and treatment.	☐True	☐False	☐Not sure
5.	Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.	☐True	☐False	☐Not sure
6.	Breast cancer survivors only need to have physical exams about once a year after they have completed breast cancer treatment.	☐True	☐False	☐Not sure
7.	Breast cancer survivors should have regular pelvic exams and pap tests (at least once a year).	☐True	☐False	☐Not sure
8.	Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.	☐True	☐False	☐Not sure
9.	Women diagnosed with breast cancer need to examine their own breasts every day.	☐True	☐False	☐Not sure
10.	Chest pain and problems with breathing can be signs of breast cancer recurrence.	☐True	☐False	☐Not sure

9. What do you think your chances are of developing heart disease (high blood pressure, stroke, heart attack, etc.)?

- ☐ I am at much less risk than others
- ☐ I am at somewhat less risk than others
- ☐ My risk is about the same as others
- ☐ I am at somewhat higher risk than others
- ☐ I am at much higher risk than others
- ☐ Not sure
- ☐ I have already been diagnosed with heart disease

10. How worried are you about developing heart disease?

- ☐ Extremely worried
- ☐ Moderately worried
- ☐ Undecided/not sure
- ☐ A little worried
- ☐ Not at all worried
- ☐ I have already been diagnosed with heart disease

Section 10

1. On a scale of 0 to 100 where 0 means "no chance" and 100 means "guaranteed to happen," how would your rate your chances of getting breast cancer again? _____

2. What do you think your chances are of being diagnosed with breast cancer again?
   - ☐ Very low
   - ☐ Low
   - ☐ Average
   - ☐ High
   - ☐ Very high
   - ☐ Not sure

3. On a scale of 0 to 100 where 0 means "not bad at all" and 100 means "the worst possible situation", how bad would it be if you were to get breast cancer again? _____

4. On a scale of 0% to 100%, what percentage of all breast cancer survivors do you think will get breast cancer again? _____

5. Compared to other women who have had breast cancer, what do you think your chances are of being diagnosed with breast cancer again?
   - ☐ I am at much less risk than others
   - ☐ I am at somewhat less risk than others
   - ☐ My risk is about the same as others
   - ☐ I am at somewhat higher risk than others
   - ☐ I am at much higher risk than others
   - ☐ Not sure

6. How worried are you about getting breast cancer again?
   - ☐ Extremely worried
   - ☐ Moderately worried
   - ☐ Undecided/not sure
   - ☐ A little worried
   - ☐ Not at all worried

7. What do you think your chances are of getting a new cancer of some other type?
   - ☐ I am at much less risk than others
   - ☐ I am at somewhat less risk than others
   - ☐ My risk is about the same as others
   - ☐ I am at somewhat higher risk than others
   - ☐ I am at much higher risk than others
   - ☐ Not sure

8. How worried are you about getting a new cancer of some other type?
   - ☐ Extremely worried
   - ☐ Moderately worried
   - ☐ Undecided/not sure
   - ☐ A little worried
   - ☐ Not at all worried

Section 11

1. How much have you heard or read about genetic testing for breast cancer risk?

- ☐ Almost Nothing
- ☐ Relatively Little
- ☐ A Fair Amount
- ☐ A lot

2. At the present time, how interested are you in getting genetic testing for breast cancer risk?

- ☐ Not at all interested
- ☐ Slightly interested
- ☐ Moderately interested
- ☐ Very interested

3. Now that such a test is currently available, which of the following best describes your intentions?

- ☐ I have already donated a blood sample for genetic testing.
- ☐ I plan to take the test as soon as possible (within the next 30 days).
- ☐ I plan to take the test sometime in the near future (within the next 6 months).
- ☐ I do not plan to take the test in the near future (not within the next 6 months).
- ☐ I do not plan to take the test at all.